

University of Nebraska - Lincoln

DigitalCommons@University of Nebraska - Lincoln

---

Nancy Shank Publications

Public Policy Center, University of Nebraska

---

10-2009

## Understanding Human Services Utilization: Opportunities for Data Sharing between Federally Funded Programs

Nancy C. Shank

University of Nebraska Public Policy Center, [nshank@nebraska.edu](mailto:nshank@nebraska.edu)

Follow this and additional works at: <https://digitalcommons.unl.edu/publicpolicyshank>



Part of the [Public Policy Commons](#)

---

Shank, Nancy C., "Understanding Human Services Utilization: Opportunities for Data Sharing between Federally Funded Programs" (2009). *Nancy Shank Publications*. 6.

<https://digitalcommons.unl.edu/publicpolicyshank/6>

This Article is brought to you for free and open access by the Public Policy Center, University of Nebraska at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Nancy Shank Publications by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.

# Understanding Human Services Utilization:



## Opportunities for Data Sharing between Federally Funded Programs

October 2009

U.S. Department of Housing and Urban Development  
Office of Special Needs Assistance Programs



## **Acknowledgements**

Understanding Human Services Utilization: Opportunities for Data Sharing between Federally Funded Programs was developed by The Cloudburst Group for the U.S. Department of Housing and Urban Development (HUD) Office of Special Needs Assistance Programs in the Office of Community Planning and Development. The primary author of this document is Nancy Shank, MBA. The author acknowledges Anne Meyers and Fawn Boyd, editors; and Sam Stewart, graphic designer.

This effort greatly benefited from involvement of numerous Federal government staff persons and representatives who contributed to this document's accuracy and comprehensiveness by identifying data standards and initiatives, clarifying information, reviewing drafts, and providing additional insights. Their contributions are greatly appreciated and acknowledged in the document herein.

Of equal benefit were the talents of the following staff of The Cloudburst Group in developing vision, providing thoughtful feedback, and providing overall leadership for the project: Michelle Hayes and Dr. Stephen Sullivan.



# Table of Contents

EXECUTIVE SUMMARY .....	1
CATALOGING EFFORT .....	5
Inclusion And Exclusion Decisions .....	6
Approach .....	7
FINDINGS .....	8
Standards By Sector .....	8
Standards By Type Of Standard .....	9
Federal Agency Involvement .....	10
Assessment of Interest .....	12
RECOMMENDATIONS .....	12
STANDARDS CATALOG .....	17
CATALOGING TEMPLATE DEFINITIONS .....	19
AGING .....	23
National Aging Program Information Systems (NAPIS) .....	25
BEHAVIORAL HEALTH .....	29
Decision Support 2000+ (DS2000+) .....	31
National Outcome Measures (NOMs) .....	35
National Reporting Program for Mental Health Statistics (NRP) .....	39
Treatment Episode Data Set (TEDS) .....	43
Uniform Reporting System (URS) .....	47
CHILD AND FAMILY SERVICES .....	51
Adoption and Foster Care Analysis and Reporting System (AFCARS) .....	53
Child Support and Court/Judicial Message Exchange Data Model .....	57
Head Start Program Information Report (PIR) .....	60
National Child Abuse and Neglect Data System (NCANDS) .....	63
National Vital Statistics System: Mortality (NVSS-M) .....	67
National Vital Statistics System: Natality (NVSS-N) .....	71
National Youth in Transition Database (NYTD) .....	75
Pediatric Nutrition Surveillance System (PedNSS) .....	79
Pregnancy Nutrition Surveillance System (PNSS) .....	83
Runaway and Homeless Youth Management Information System (RHYMIS) .....	87
Statewide Automated Child Welfare Information Systems (SACWIS) .....	91
COMMUNITY RESOURCES .....	95
Alliance of Information and Referral Systems Standard (AIRS XSD) .....	97
National Information Exchange Model (NIEM) .....	101
CORRECTIONS .....	107
Corrections Technology Association Corrections Data Exchange Standards Project .....	109
National Information Exchange Model (NIEM) .....	111
CRIMINAL .....	117



# Table of Contents



JUSTICE/COURTS .....	117
Child Support and Court/Judicial Message Exchange Data Model .....	119
Justice Reference Architecture (JRA) .....	123
Law Enforcement Information Sharing Program (LEISP) Exchange Specifications (LEXS) .....	127
Law Enforcement National Data Exchange (N-DEx) .....	131
National Information Exchange Model (NIEM) .....	135
Uniform Crime Reports (UCR)/ National Incident-Based Reporting System (NIBRS) .....	141
EMERGENCY/DISASTER .....	145
ANSI-Homeland Security Standards Panel (ANSI-HSSP) .....	147
Common Alerting Protocol (CAP) .....	151
Coordinated Assistance Network Standard (CAN XML) .....	155
Disaster Surveillance Forms .....	159
Emergency Data Exchange Language (EDXL) .....	163
Epidemic Information Exchange (Epi-X) .....	169
Health Alert Network (HAN) .....	173
National Electronic Disease Surveillance System (NEDSS) .....	177
National Information Exchange Model (NIEM) .....	181
EMPLOYMENT/WORKFORCE TRAINING .....	187
Workforce Investment Act Data Reporting and Validation System (DRVS) .....	189
FOOD AND NUTRITION PROGRAMS .....	193
Pediatric Nutrition Surveillance System (PedNSS) .....	195
Pregnancy Nutrition Surveillance System (PNSS) .....	199
Supplemental Nutrition Assistance Program (SNAP) .....	203
Women, Infants, and Children Program (WIC) .....	205
HEALTH CARE .....	209
ASC X 12N Transaction .....	211
Certification Commission for Healthcare Information Technology (CCHIT) .....	215
Clinical Document Architecture (CDA) .....	219
Clinical Reporting System (CRS) .....	223
Consolidated Health Informatics (CHI) .....	227
Continuity of Care Document (CCD) .....	233
Continuity of Care Record (CCR) .....	237
Electronic Healthcare Network Accreditation Commission (EHNAC) .....	241
Federal Health Architecture (FHA) .....	245
Health Information Technology Standards Panel (HITSP) .....	249
Health Level (HL7) .....	257
Integrating the Healthcare Enterprise (IHE) .....	263
Medicaid Analytic Extract (MAX) extracted from the Medicaid Statistical Information System (MSIS) .....	267
Medicaid IT Architecture (MITA) .....	271



# Table of Contents

Medicare Data Files .....	275
National Committee on Vital and Health Statistics (NCVHS) .....	279
National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT) .....	283
National eHealth Collaborative (NeHC) .....	287
Nationwide Health Information Network (NHIN) .....	291
Ryan White Program .....	295
SCHIP Statement of Expenditures (CMS-21) .....	299
HOUSING/SHELTER .....	303
Client Activity Reporting System (CARS) .....	305
Form HUD-50058 .....	309
Homeless Management Information System XML (HUD HMIS XML) .....	313
Low Income Home Energy Assistance (LIHEAP) Program Performance .....	317
Weatherization Assistance Program .....	321
INCOME SUPPORT .....	325
Temporary Assistance for Needy Families (TANF) and Tribal TANF .....	327
PUBLIC HEALTH .....	331
Disaster Surveillance Forms .....	333
Epidemic Information Exchange (Epi-X) .....	337
Health Alert Network (HAN) .....	341
National Electronic Disease Surveillance System (NEDSS) .....	345
National Vital Statistics System: Mortality (NVSS-M) .....	349
National Vital Statistics System: Natality (NVSS-N) .....	353
Pediatric Nutrition Surveillance System (PedNSS) .....	357
Pregnancy Nutrition Surveillance System (PNSS) .....	361
Public Health Data Standards Consortium (PHDSC) .....	365
Public Health Information Network (PHIN) .....	369
APPENDIX A .....	373
APPENDIX B .....	377
APPENDIX C .....	391
APPENDIX D .....	399





## EXECUTIVE SUMMARY

In communities across the United States, social service clients face uncoordinated systems of care and delays in services when their information cannot easily be shared among providers. Social service agencies face challenges in sharing information on clients and services between disparate information systems and inefficiencies when multiple, stand-alone systems are used to satisfy operational, funding, or reporting requirements.

This cataloging project arose from the U.S. Department of Housing and Urban Development's (HUD's) interest to document standards that may be of relevance to its community partners, particularly those partners working to support local homeless, housing, and community development activities and build bridges between and among disparate information systems. It is hoped that this catalog will assist HUD policymakers and their community partners to identify data sharing opportunities. This document may also be of interest to other community organizations (beyond homeless organizations) attempting to build communitywide information systems and to other federal agencies and standards organizations across the United States. Documentation may assist policymakers in identifying alliances and collaborations. Successful data sharing may facilitate the evaluation of worthwhile social policy research. The information in this catalog is intended to be accessible to a nontechnical audience. When available, links to technical data specifications are provided.

This catalog represents an effort to provide accurate and comprehensive information about relevant data standards and initiatives. However, the status of these standards and initiatives is rapidly changing. Therefore, it is hoped that the catalog might be periodically updated to reflect new information or developments.

HUD's Office of Special Needs Assistance Programs (SNAPs) defines how grantees funded under the McKinney-Vento Homeless Assistance Act collect data about the persons they serve. HUD requires these grantees to collect certain core data elements and has also created technical data interoperability standards to facilitate information sharing between local community organizations serving the homeless. The data requirements and standards, labeled *Homeless Management Information Systems (HMIS) Data and Technical Standards*, set a foundation to capture uniform and consistent data on homelessness throughout the country. Beyond the homeless services community, other sectors similarly have established reporting and technical standards. Documentation of major data requirements and standards begins to define the many ways community agencies may be collecting and reporting information about clients. When standards are reconciled, the solution may then be used by communities across the United States to streamline access to services for clients.

This report focuses on national client-level health and human service data requirements and standards, many of which are endorsed or sponsored by federal agencies. The term *standard* is used somewhat loosely throughout this report. *Standard* is not limited to technical standards. Rather, standard is used to refer to any initiative or program that defines how data are collected or maintained in communities for the provision of health and human services.





The bulk of this report is a catalog of major health and human service standards. Content for each catalog entry was gleaned from documents and Web sites. Whenever possible, the summaries were reviewed by representatives of sponsoring organizations.

In total, 64 standards were included in the standards catalog. Standards were identified for 13 sectors:

- Aging
- Behavioral Health
- Child and Family Services
- Community Resources
- Corrections
- Criminal Justice/Courts
- Emergency/Disaster
- Employment/Workforce Training
- Food and Nutrition
- Health care
- Housing/Shelter
- Income Support
- Public Health

The narrative portion of this report describes the cataloging effort and results and concludes with six recommendations for next steps. The recommendations focus on efforts that may forge data sharing relationships between HUD and its community partners and other federal and local agencies. The recommendations include:

1. Prioritize standards of most relevance and interest to HUD and its grantees.
2. Compare priority standards to the HUD HMIS standards and develop strategies for how standards may interact.
3. Document best practices in community data sharing efforts that include data on homeless men, women, and children.
4. Participate in, and develop, data sharing dialogues with other health and human services standards efforts.
5. Document challenges and solutions to community information sharing.
6. Identify additional data resources that may help communities and HUD document homelessness in the United States.





## BACKGROUND

Continuums of Care (CoCs) were created by the U.S. Department of Housing and Urban Development (HUD) to develop community-based approaches to comprehensively address the needs of homeless people. Continuums are partnerships of localities, states, and nonprofit organizations, funded by grants from HUD's Office of Special Needs Assistance Programs. A *Continuum of Care* (CoC) is defined by HUD as:

A community plan to organize and deliver housing and services to meet the specific needs of people who are homeless as they move to stable housing and maximum self-sufficiency. It includes action steps to end homelessness and prevent a return to homelessness.

A CoC serves three main purposes:

7. It is a strategic plan for addressing homelessness in the community based on the identified needs of homeless individuals and families, the availability and accessibility of existing housing and services, and the opportunities for linkages with non-homeless mainstream housing and service resources;
8. It is a strategic process to develop a broad based, communitywide, year-round initiative; and,
9. It is an application to HUD for homeless-targeted housing and services resources.

The ability of CoCs to effectively address the needs of homeless persons is enhanced when there is coordination with other social services organizations beyond the homeless service community. However, CoCs have been challenged to fully coordinate client services with those offered by social service providers outside the homeless network. Part of the challenge has been the difficulty for CoCs to electronically share information about clients and services. Clients find that they need to repeat their stories over and over in order to access needed services. Helping professionals are often stymied in their ability to coordinate care because they are unable to easily share client and service system information. This leads to delayed or undelivered services that may negatively impact client outcomes.

HUD has taken major steps to improve client information sharing within the nation's homeless delivery system. In the early 1990s, HUD funded a pilot to implement information systems in local communities to obtain unduplicated communitywide data on homeless populations in local jurisdictions. In 2001, Congress directed HUD to work with all communities to collect better homeless data through support of local Homeless Management Information Systems (HMIS). HUD made federal homeless funds available to communities to implement HMIS, and subsequently mandated that CoCs implement these systems. HMIS systems are implemented as locally administered data collection and reporting systems, not as a national database. Through local HMIS agreements community organizations create privacy and data sharing protocols. Local HMIS are



guided by National Homeless Management Data and Technical Standards<sup>1</sup> published in the Federal Register. The standards define baseline requirements for data collection, privacy, and security of locally administered systems.

In 2005, HUD also developed the HUD HMIS XML<sup>2</sup> data standard, based on Universal Data Elements. By mid-2007, several vendors had incorporated the HMIS XML schema. The HUD HMIS XML may serve as a foundation for exchanging information with service providers beyond Continuums, even though they do not observe the HUD HMIS XML. Other community organizations may observe different health and human services data standards. But the presence of other standards, even if overlapping or conflicting with HUD standards, provides an opportunity: When a standard exists, data elements may be mapped once and then used by others. *Data mapping* is the process of comparing data elements from different models and determining how they relate to each other. Data elements with like information may be technologically connected (that is, *mapped*) to each other. As homeless agencies attempt to coordinate client services beyond the homeless delivery system, the HUD HMIS standards will be useful in “mapping” what data may be exchanged with organizations not using the standard.

Even with the existence of standards and standards mapping, there remain challenges to data sharing. Indeed, many experts believe that solving the data reconciliation issues is only a small part of the multitude of challenges that must be addressed when organizations want to share information. These issues include: protecting the privacy and confidentiality of client information, creating information technological infrastructures, ensuring quality and meaning of data, developing client matching strategies, and identifying funds to pay for the costs of data exchange. Appendix A includes a brief discussion of these challenges.

As a national standard, the HUD HMIS will increasingly interact with other widely adopted standards. Understanding the purposes of relevant national health and human services standards will enable HUD and their programs and communities to more knowledgeably approach and prioritize data sharing efforts.

---

<sup>1</sup> <http://www.hud.gov/offices/cpd/homeless/lawsandregs/fr4848-n-02.pdf>

<sup>2</sup> eXtensible Mark-up Language (XML) is convention for tagged and defining data elements. XML is self-descriptive, meaning that XML users have flexibility in their naming and defining (unlike, for example, HTML where there are pre-set tag names and meanings). XML also uses plain text format, making it accessible to casual users and providing a good basis for interoperability. The use of XML has increased dramatically, and XML is used to enable data sharing across the spectrum of types of users.





## CATALOGING EFFORT

What are the other data standards that community health and human services organizations observe? Do these standards provide an opportunity for communities to more efficiently and comprehensively serve clients through client data sharing? Are there partnerships HUD and CoCs might develop to further their efforts to better understand the extent and nature of homelessness? This report begins to answer these questions by cataloging major health and human services data standards that may intersect with HUD Homeless Management Information System standards. The emphasis of this cataloging effort is client-centered data collected during service encounters.

This catalog is designed to assist HUD policymakers and their community partners identify data sharing opportunities. Other community organizations and federal agencies, beyond homeless organizations, may also find this catalog a valuable documentation of standards as they attempt to share data. The catalog may assist policymakers in identifying alliances and collaborations. Successful data sharing may facilitate the evaluation of worthwhile social policy research.

For the purposes of this report, *standards* include a range of ways that client or services data may be structured. The term *standards* is not used only in the technical sense, that is, to refer to data standards that describe data structures within electronic systems. Rather, this catalog attempts to capture the multitude of efforts that, in some way, promulgate data that are collected in the provision of human services. For example, this catalog includes federal reporting requirements. It also includes overarching frameworks that, on a macro level, describe the interrelationships of data. Important initiatives, such as harmonization and certification efforts, are also included because these organizations are often at the forefront of deciding which standards are promoted to broader usage. The catalog uses the following definitions for *types of standards*:

- **Reporting Requirements or Reporting Standards.** Reporting standards are the “fields” of information collected, often by federal agencies, to provide aggregated information about clients and services provided. These reporting standards may commonly be referred to as reporting requirements.
- **Data Interoperability Standards/Suites of Standards.** Data interoperability standards are created for the purpose of technically defining the type of data and the required attributes of data for the purpose of exchange between computer information systems.
- **Overarching Frameworks.** Overarching frameworks cast an overall vision for the relationships between data users and owners, data, and information exchange. Overarching frameworks are often used to indicate how standards should enable data sharing.
- **Standards Development Organizations or Standards Harmonization Efforts.** Standards development organizations or standards harmonization efforts are not standards, in and of themselves, but are organizations who either author or combine standards for use in an industry.



The work of these organizations is crucial to standards process, because these organizations play key roles in establishing, maintaining, promoting, and giving credibility to standards.

- **Certification Organizations.** Certification organizations evaluate the compliance of technology products to standards. As with Standards Development Organizations and Standards Harmonization Efforts, these organizations are not standards in and of themselves, but use standards. Because the work of Certification Organizations is crucial to widespread, compliant adoption of standards, their efforts are included in this catalog.

## Inclusion And Exclusion Decisions

Many community organizations collect a multitude of data about the clients that they serve. Some community organizations develop internal client tracking systems that are independent of any reporting requirements or national standards. However, many community organizations must collect data that complies with standards developed by others. This catalog attempts to identify the most pervasive standards that focus on:

- **Nationally or internationally observed** standards, rather than standards that may be community grown and variant across the United States.
- **Operational or administrative** standards, meaning that the standards are used to collect and track information about clients to document their eligibility for health and human services, use of health and human services, and/or outcomes of health and human services program provision.
- Standards that are **authored or endorsed by federal agencies** or are in wide use by programs receiving public funding.

Specifically, not included in this cataloging effort are standards and data collected through surveys, since most **surveys** are samples of a population collected for research purposes, rather than data collected for all clients used for operational or administrative purposes. Also not included are **technological standards** that focus on how information systems communicate, rather than those having primarily a client focus (but which may be underpinned by technological standards). **Classifications/Taxonomies**, Nomenclatures/Terminologies, and Data Dictionaries have also been excluded from cataloging. Classifications/Taxonomies are ordered systems that show the natural and hierarchical relationships between concepts. For example, the LA 211/AIRS Taxonomy of Health and Human Services is the most widely used taxonomy for services in North America; however, this classification of services is not included as a cataloged standard because it is a classification rather than a client-focused standard. Finally, Nomenclatures/Terminologies and Data Dictionaries are not included in this catalog. **Nomenclatures/Terminologies** and **Data Dictionaries** are conventions for naming to ensure that terms mean the same thing, even when used by different people across settings. SNOMED-CT (Systematized Nomenclature of Medicine—Clinical Terms) for example, is a comprehensive clinical terminology that ensures clinicians use consistent terminology. However, since SNOMED-CT is the terminology used to describe clinical terms, rather





than data collected about patients, it and other nomenclatures and terminologies are not included in the catalog. Standards that had been considered for inclusion in the catalog but that ultimately did not meet the criteria for inclusion are summarized in Appendix B.

## Approach

A variety of approaches were used to identify and select the standards used in this catalog. Experts within particular health and human services sectors were contacted for their input on important standards efforts. Experts included leadership of national associations, technology experts, consulting organizations, vendors, standards sponsors, and academicians. A literature review and Web-based Internet search were conducted, using a variety of search terms.

A number of specific service sectors were targeted as particularly relevant for this cataloging effort. The initial sectors that were identified were: aging, behavioral health, case management, child and family services, community resources, corrections, criminal justice/courts, domestic violence, education, emergency/disaster, employment/workforce training, food and nutrition programs, health care, housing/shelter, income support, public health, transportation, and veterans. Ultimately, standards were not identified for all of these areas.

The content of the catalog was largely gleaned from examination of organizationally endorsed documentation and Web sites. In order to confirm the validity of the information captured in the catalog, persons representing each standard were contacted and asked to review the information for completeness and accuracy. The catalog includes a “Reviewed” field that indicates whether each standard was reviewed by a person associated with the effort. In most instances, the individual reviewing the catalog entry is also the contact person.

The catalog information is written to be accessible to a nontechnical audience. Therefore, the information focuses on how the information is developed and used, rather than the technical processes that may underlie the standards.

The information in this catalog is a snapshot of standards and initiatives. Many of the projects cataloged are extremely dynamic processes which are quickly changing. For example, the American Recovery and Reinvestment Act of 2009 codifies two new federal advisory committees (the Health Information Technology Standards Committee and the Health Information Technology Policy Committee). Important information about their work will emerge in coming weeks. Because of the rapid changes happening in health care and all the sectors, it is hoped that this catalog may continue to be updated as new information becomes available.





## FINDINGS

In total, 64 standards were included in the standards catalog. Standards were identified for 13 sectors:

- Aging
- Behavioral Health
- Child and Family Services
- Community Resources
- Corrections
- Criminal Justice/Courts
- Emergency/Disaster
- Employment/Workforce Training
- Food and Nutrition
- Health care
- Housing/Shelter
- Income Support
- Public Health

### Standards By Sector

The 21 standards related to Health care represent the largest number of standards within a sector. Some standards are reported in more than one sector. For example, the Child Support and Court/Judicial Message Exchange Data Model is included both as a *Child and Family Services* standard as well as a *Criminal Justice/Courts* standard.

The numbers of standards relating to each sector is shown in Table 1.

*Table 1. Number of Standards Identified for Each Sector*

Sector	Number of Standards Identified
Aging	1
Behavioral Health	5
Child and Family Services	11
Community Resources	2
Corrections	2
Criminal Justice/Courts	6





Emergency/Disaster	9
Employment/Workforce Training	1
Food and Nutrition Programs	4
Health care	21
Housing/Shelter	5
Income Support	1
Public Health	10

## Standards By Type Of Standard

Standards, for the purposes of this catalog, include the following types of efforts:

- Reporting Standards
- Data Interoperability Standards/Suites of Standards
- Overarching Frameworks
- Standards Development Organizations or Standards Harmonization Efforts

Of these four types of standards, the 33 *Reporting Standards* make up the largest number identified. Some standards are included in more than one type. For example, the National Information Exchange Model (NIEM) is both a data interoperability standard and an overarching framework. The numbers of standards relating to each sector is shown in Table 2.

*Table 2. Number of Types of Standards Identified*

Standard Type	Number of Standards Identified
Reporting Standards	33
Data Interoperability Standards	16
Overarching Frameworks	6
Standards Development Organizations/ Harmonization Efforts	9
Certification Organizations	1

Appendix C has a complete listing, by sector, of each standard identified for the catalog. Appendix D is an alphabetical listing of each standard, its sector and type categorization.



## Federal Agency Involvement

Many, but not all, standards identified have involvement from a federal agency. The involvement may be as a sponsor of the standard, an adopter of the standard, or a funder of the process. Sponsorship is the most intense involvement as it typically implies an ownership and ongoing management of the standard. In some cases, federal agencies may jointly sponsor a standard, as is the case with the National Information Exchange Model (NIEM), which is a joint venture of U.S. Department of Homeland Security and the U.S. Department of Justice. Federal agencies may also fund the development of a standard that is then maintained by a nonfederal agency, as is the case with the National eHealth Collaborative (NeHC) which is funded, in part, with support from the U.S. Department of Health and Human Services.

Of the standards identified, the U.S. Department of Health and Human Services sponsors, by far, the greatest number of standards (44). The federal sponsorship of standards relating to each sector is shown in Table 3.

*Table 3. Federal Department Sponsorship of Standards, by Sector*

Sector	Agriculture	Energy	Health and Human Services	Homeland Security	Housing and Urban Development	Justice	Labor
Aging			1				
Behavioral Health			5				
Child and Family Services			11	1		1	
Community Resources							
Corrections							
Criminal Justice/Courts			1	1		5	
Emergency/Disaster			4	3		1	
Employment/Workforce Training							1
Food and Nutrition Programs	2		2				
Health care			9				
Housing/Shelter		1	1		3		
Income Support			1				
Public Health			9				
TOTAL	2	1	44	5	3	7	1





*Table 4. Federal Agency Sponsorship of Standards*

Department	Agency	Number of Standards Sponsored
Agriculture	Food and Nutrition Services	2
Energy	Office of Energy and Renewable Energy	1
Health and Human Services	Administration for Children and Families	9
	Agency on Aging	1
	Centers for Disease Control and Prevention	9
	Centers for Medicare and Medicaid Services	4
	Health Resources and Services Administration	1
	Indian Health Services	1
	National Committee on Vital and Health Statistics	1
	Office of the National Coordinator for Health Information Technology	2
	Substance Abuse and Mental Health Services Administration	5
	Science and Technology Directorate	3
Housing and Urban Development	Federal Housing Administration	1
	Office of Community Planning and Development	1
	Office of Public and Indian Housing	1
Justice	Federal Bureau of Investigation	2
	Office of Justice	2
Labor	Employment and Training Administration	1
Office of Management and Budget		1



## Assessment of Interest

As part of this effort, persons from each organization were invited to review their catalog entry. In total, 17 of the catalog entries were reviewed by persons associated with the standard. A number of persons were extremely interested in the concept of coordinating their data with homeless data. Although assessment of interest in collaborating with HUD was not a formal part of the cataloging effort, it may well be that HUD will find some ready partners in exploring data sharing opportunities for local CoCs.

## RECOMMENDATIONS

This report identifies and catalogs major health and human services data standards relevant to the HUD HMIS XML standard. Particular focus was paid to standards used in the provision of client services. In total, 64 standards representing 13 sectors of health and human services delivery areas were identified.

HUD has an interest in creating data sharing opportunities for Continuums of Care to other community organizations who also serve the homeless population. To further HUD's goal, six recommendations are offered:

- 10. Prioritize standards of most relevance and interest to HUD and its grantees.** Some of the standards identified in this catalog will be of more interest to HUD and CoCs than will others. Many standards efforts are rapidly responding to changing environments. HUD should determine where it may best forge relationships with other organizations and agencies around information sharing. A small workgroup of HUD officials and sophisticated CoC data experts should be convened to prioritize the standards initiatives and action steps.
- 11. Compare priority standards to the HUD HMIS standards and develop strategies for how standards may interact.** As priority standards are identified, a high-level comparison of the HUD HMIS standard to these other standards should be made. What are the areas of overlap? Where are their gaps in data? How do the data structures compare? HUD HMIS XML and other standards may interact in a variety of ways. Some of the strategies for interacting may include:
  - a) Developing technical "mapping" translation documents that would convert data into a format that may be transferred between two standards;
  - b) Referring to aspects of other standards that are superior to what HUD might author (an existing example of this within the HUD HMIS XML is the referencing of the AIRS Taxonomy for identifying type of services that organizations offer);
  - c) Harmonizing efforts that would create an overall Human Services XML to enable and advance interoperability through definition of a data set and which standards will be used to represent it; or,
  - d) Affiliating HMIS standards with other frameworks or harmonization efforts, such as the National Information Exchange Model.





**12. Document best practices in community data sharing efforts that include data on homeless men, women, and children.** There are a number of communities and states that are crossing the HMIS threshold to share client information with other health and human service organizations. These successful efforts should be documented, highlighting how standards played a role in facilitating effective data sharing. HUD's *Community Spotlights* (found at <http://www.hmis.info/>, under "Resource Type" or <http://www.hmis.info/Default.aspx?classicAsp=resources.aspQStringrest=1^rtid=6>) provide information about some community data sharing initiatives, but additional efforts should be made to promote these successes. Additional efforts might include:

- a) Convening a Community Best Practices Meeting that could showcase local community data sharing initiatives including highlights of lessons learned. The presentation materials could then be posted and made readily available on both the HUD Homeless ([www.HUDHRE.Info](http://www.HUDHRE.Info)) and HMIS ([www.HMIS.Info](http://www.HMIS.Info)) Web sites.
- b) Development of a Comparative Case Study report to document how HMIS systems are operating as a part of the human services networks in communities. Documentation of models might be particularly helpful to showcase how HMIS data are reusable<sup>3</sup> in multiple contexts, thus promoting the benefits, knowledge, and efficiencies well-managed HMIS may offer communities. Reusable data may also be more likely to be cross-validated as they are carried across different operational or administrative units of an organization.
- c) Deployment of a data sharing Web resource library that maintains information about how HUD and its grantees are working to securely share HMIS data with other mainstream and human services systems to improve client outcomes. The Web resource could serve as a valuable tool for other communities and could be modeled from the U.S. Health and Human Services Agency for Healthcare Research and Quality (AHRQ) National Resource Center for Health Information Technology (<http://healthit.ahrq.gov/>). This may be accomplished through a partnership with National Human Services Data Consortium's Human Services XML Committee (HS XML).
- d) A demonstration project or innovation in services funding mechanism could be created to support community sharing projects and dissemination of outcomes. Funds could be specifically focused on CoCs that are using existing standards to share data beyond HMIS systems. Projects should include access to technical assistance, strong evaluations, and participation in dissemination activities.
- e) Creating a community of practice for CoCs that are sharing data about clients using standards. A community of practice will assist CoCs increase knowledge and accelerate effective implementations.

**13. Participate in and develop data sharing dialogues with other health and human services standards efforts.** Nationally, there are a multitude of conversations about how to improve electronic information exchange in health and human services. HUD and CoCs have participated in some of these dialogues and

<sup>3</sup> Reusable data is data that is collected for more than just one purpose. For example, reusable data may be collected and used by different levels of the same organization: for client tracking, reimbursement, and quality measurement. Reusable data may also include data that is collected by one organization, but shared with other organizations to serve other purposes. Reusable data are more cost-efficient and more likely to be adopted by users.





should continue to be an active and vocal presence.

- a) Create agency-to-agency dialogues at the national level with priority initiatives to explore opportunities.
- b) Identify national meetings and committees that have client information sharing as a goal. HUD should establish a presence at these meetings and ensure that other initiatives are aware of HUD's work with HUD HMIS XML and other sharing initiatives.
- c) Convene a meeting with the particular focus of community data sharing with representatives of other standards with an express interest in exploring improved community and national information sharing.

**14. Document challenges and solutions to community information sharing.** There are multiple challenges to sharing client data between information systems. The presence of standards helps, but does not ensure, successful data sharing. Some of these challenges are briefly described in Appendix A. HUD and its communities should jointly determine how to address these challenges. Such documentation should be completed for three purposes: 1) to assist HUD and Continuums of Care in acknowledging issues that must be addressed when considering exchanging information; 2) to document HUD's requirements, where appropriate, so that compliance with those requirements is asserted as a necessary condition for information exchange; and 3) to describe what resources or other solutions may be applied to resolve the challenges.

**15. Identify additional data resources that may help communities and HUD document homelessness in the United States.** The focus of this cataloging report is on information sharing during day-to-day operational service encounters. However, the vast information gathered through HUD HMIS communities may also serve as an important resource for post-hoc data sharing with other data sets. Among the data that are available from federal agencies, there may be important opportunities for collaboration at the federal and community level. Data could be made available to policymakers, researchers, and others interested in creating knowledge about homelessness in the United States. Data Web sites and guides have been developed by other federal departments to spur information sharing. Three notable examples are:

- a) The Federal Interagency Forum on Aging Related Statistics created *Data Sources on Older Americans 2006* ([http://www.agingstats.gov/agingstatsdotnet/Main\\_Site/Data/2006\\_Documents/DS\\_OA\\_2006.pdf](http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/2006_Documents/DS_OA_2006.pdf)), a guide that details government-sponsored surveys and products that contain statistical information about the older population.
- b) The Federal Interagency Forum on Child and Family Statistics sponsors the [www.childstats.gov](http://www.childstats.gov) Web site. The Forum, established under Executive Order No. 13045, has a mission to foster coordination and collaboration and to enhance and improve consistency in the collection and reporting of federal data on children and families. The Forum also aims to improve the reporting and dissemination of information on the status of children and families.
- c) The National Center for Education Statistics is the primary federal entity for collecting and analyzing data related to education in the United States. The Center maintains *NCES Handbooks Online* (<http://>





nces.ed.gov) to serve the research, education, and other interested communities.

This report identifies major health and human service standards being observed by helping organizations in every American community. Working together to improve data sharing among these initiatives may reduce duplicative efforts and improve client outcomes.



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# STANDARDS CATALOG





## CATALOGING TEMPLATE DEFINITIONS

**Name:** Official name of the standard

**Sector:** Listing of service sector or populations the standard is mostly closely associated with. Sectors include: Aging, Behavioral Health, Child and Family Services, Community Resources, Corrections, Criminal Justice/Courts, Emergency/Disaster, Employment/Workforce Training, Food and Nutrition Programs, Health care, Housing/Shelter, Income Support, and Public Health.

**Type of Standard:** Categorization of the standard, based on the purposes achieved by the standard:

- **Reporting Requirements and Reporting Standards.** Reporting standards are the “fields” of information collected, often by federal agencies, to provide aggregated information about clients and services provided. These reporting standards may commonly be referred to as reporting requirements.
- **Data Interoperability Standards.** Data interoperability standards are created for the purpose of technically defining the type of data and the required attributes of data for the purpose of exchange between computer information systems.
- **Overarching Frameworks.** Overarching frameworks cast an overall vision for the relationships between data users and owners, data, and the exchange of data. Overarching frameworks are often used to indicate how standards should enable data sharing.
- **Standards Development Organizations or Standards Harmonization Efforts.** Standards development organizations or standards harmonization efforts are not standards in and of themselves, but are organizations who either author or combine standards for use in an industry. The work of these organizations is crucial to standards process, because the organizations play key roles in establishing, maintaining, promoting, and giving credibility to standards.
- **Certification Organizations.** Certification organizations evaluate the compliance of technology products with standards. As with Standards Development Organizations and Standards Harmonization Efforts, these organizations are not standards in and of themselves, but reference standards.

**Sponsor:** Name of the organization responsible for maintaining the standard.

**Purpose:** The rationale for the standard and what it is intended to accomplish.

**Version:** The name of the current version of the standard.

**Year Current Version was Adopted:** The year the current version of the standard was adopted.





**Age of Standard:** The year that the standard was first promulgated.

**Federal Involvement/Endorsement:** A description of what federal agencies are involved in maintaining, developing, endorsing, or otherwise supporting the standard.

**Who Uses:** A description of the types of organizations or other users that organize or share data according to the standard.

**Mandatory/Voluntary (and Authorization):** A description of whether use of the standard is mandatory or voluntary to users. If the standard is mandatory, the authorization should be described.

**Estimate of Adoption:** A description of how widely the standard has been adopted by users.

**Standards Development Process:** A description of the process by which changes are made to the standard such as input processes, who must approve, and how vendors are involved.

**Type of Content:** A high-level description of the data.

**Unit of Collection:** A description of the level of granularity of the data that are collected. For most health and human services standards, the unit of collection may be at the encounter, client, program, and/or organizational levels.

**Data Availability:** The data that are available to users and others who may be interested in sharing information.

**Relationship to Other Standards:** Some standards use or reference other standards. This is a description of whether the standard is, in some way, using or building upon other standards.

**Future Plans:** A description of changes (new versions, expansions, and so forth) planned for the standard.

**Vendors Incorporating In Products:** A brief description as to whether commercial vendors use the standard in product development or maintenance.

**Key Documents and Reports:** Listing and descriptions of recent or key information about the standards and information based on data collection using the standard.

**Web Site:** The primary Web site to locate information about the standard.





**For More Information:** A contact person, in most cases from the sponsoring organization, who is available to discuss the standard.

**Reviewed:** Was the catalog summary reviewed by a representative of the standard?



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# AGING





# National Aging Program Information Systems (NAPIS)

## **Sector**

Aging Population

## **Type of Standard**

Reporting Requirements or Reporting Standards

## **Sponsor**

U.S. Department of Health and Human Services, Administration on Aging

## **Purpose**

The National Aging Program Information Systems and State Performance Reports system is a reporting system on Older Americans Act services delivered by the state and their sub-state Area Agencies on Aging.

## **Version**

The specification was last revised in fiscal year 2005.

## **Year Current Version Was Adopted**

2005

## **Age of Standard**

OMB Approval Number 0985-0008, expires 5/31/2010

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration on Aging

## **Who Uses**

Reported annually by states and territories to the Administration on Aging. States collect local-level data through their state-funded Area Agencies on Aging. Area Agencies on Aging collect data from their contracted and grantee providers. Data are used to develop performance indicators shared with Congress and decision makers. State and local decision makers use data at the local level.

## **Mandatory/Voluntary (and Authorization)**

Mandatory

## **Estimate of Adoption**

All states use NAPIS for reporting services





## **Standards Development Process**

OMB approval

## **Type of Content**

Unduplicated characteristics and counts of clients: About 10 million clients identified. More detailed information collected on about 3 million clients including: client demographics including age, race, ethnicity, poverty, live-alone status, and number of ADL. Total service units, utilization and federal and total expenditure profiles, network profiles, and accomplishments are reported. Individual data are not reported.

## **Unit of Collection**

Individual, but reported as organizational and statewide aggregates

## **Data Availability**

Detailed data tables with aggregated totals are available through the Administration on Aging Web site. Online query system for multiple years of data available at: [www.data.aoa.gov](http://www.data.aoa.gov)

## **Relationship to Other Standards**

None

## **Future Plans**

AoA will be updating NAPIS data collection specifications in FY09, effective for FY 2010.

## **Vendors Incorporating In Products**

Yes. Vendors offer products that assist states in managing their cases and perform reporting requirements.

## **Key Documents and Reports**

Reporting Requirements: [http://www.aoa.gov/PROF/agingnet/NAPIS/docs/SPR-Modified-Form-06\\_08\\_2007.pdf](http://www.aoa.gov/PROF/agingnet/NAPIS/docs/SPR-Modified-Form-06_08_2007.pdf)

## **Web Site**

U.S. Department of Health and Human Services, Administration on Aging: <http://www.aoa.gov/prof/agingnet/NAPIS/napis.aspx> and <http://www.data.aoa.gov> (select AGing Integrated Database (AGID))





### **For More Information**

Valerie Cook, Office of Evaluation  
Administration on Aging  
One Massachusetts Avenue NW  
Washington, DC 20201  
Telephone: (202) 357-3583  
Facsimile: (202) 357-3549  
E-mail: [Valerie.Cook@aoa.hhs.gov](mailto:Valerie.Cook@aoa.hhs.gov)

### **Reviewed**

Yes



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# BEHAVIORAL HEALTH





## Decision Support 2000+ (DS2000+)

### Sector

Behavioral Health

### Type of Standard

Overarching Framework

### Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics, and in collaboration with Abt Associates Inc., and National Association of State Mental Health Program Directors - Research Institute.

### Purpose

Decision Support 2000+ (DS2000+) responds to the mental health field's lack of standardized data, uniform measures, and an accessible and effective information system. DS2000+ makes use of existing information technology and data collection activities and allows users to bring their current practices closer to their ideal without major overhauls and massive investments. DS2000+ is developing data standards, core data recording requirements, procedures, and an information system for mental health services. DS2000+ is a new information system that supports the public health model and facilitates the collection, analysis, and reporting of mental health data, from population characteristics through service outcomes. Data will be linked with standards of practice, instruments for evaluating care, and data from other human services. Therefore, Decision Support 2000+ is a single comprehensive system that will satisfy all mandated reporting requirements.

### Version

DS2000+ does not yet exist in operational form. It is currently a proposed framework for an information infrastructure, with a set of standard definitions, uniform operations, and quality measurement tools that will support the public health model, facilitate decision making, provide feedback, enhance communication, and thereby improve the quality of mental health care. DS2000+ is under development. Collaborators have completed a requirements analysis for the system and now are reaching out to the mental health community to make it ready for implementation.

### Year Current Version was Adopted

Not applicable

### Age of Standard

Not applicable



## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics

## **Who Uses**

Many of the data elements are routinely collected by states, managed behavioral healthcare organizations, the federal government, and others.

## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

All states have now voluntarily adopted many of these standards. The technology for linking components, transforming data, and producing reports exists. DS2000+ does not create something new, but rather, recommends ways to bring uniformity to what is now not standardized and to link what is now disconnected.

## **Standards Development Process**

CMHS, the Mental Health Statistics Improvement Program (MHSIP) Policy Group, and Regional User Groups (RUG), and a Technical Expert Workgroup review revisions.

## **Type of Content**

“Core” data are those critical data elements that would be used by all stakeholders to make personal, clinical, or managerial decisions and to evaluate the quality of care; “stakeholder-specific” data are also critical, but primarily of interest to a particular stakeholder or user group (for example, state and local mental health authorities, consumers and families, providers, insurers, and managed behavioral healthcare organizations). The key information modules are:

- population-based core data set and plan enrollment core data set for persons enrolled in health and behavioral healthcare plans;
- encounter core data set and the related financial core data set, organizational core data set, and human resource core data set;
- core data sets for clinical and system guidelines that reflect adherence to best practices in each of these; and
- core data sets on results, including a consumer outcome core data set, a report card core data set (including surveys of consumers, providers, and others), and a performance measure core data set.





## Unit of Collection

DS2000+ recommends standards for data recording that permit information reporting at the person, health plan, local, state, and national levels, including core data sets, measures and instruments, and procedures for collecting and analyzing data.

*Population data* will describe demographic characteristics, medical and mental health status and level of functioning, as well as quality of life of community members. *Enrollment data* will describe demographic, insurance, and baseline health and mental health status of enrollees and their family members. *Encounter data* will characterize all users of services (for example, health and mental health status, diagnosis, symptoms, functional status, ad so forth), types of services used, and frequency of use. *Financial data* will reflect costs of services, administrative costs, other expenditures, and revenues. *Human resource data* will describe the characteristics of providers of care, support staff, and other personnel. Information about organizational structure and process will be reflected by *organizational data*. *Clinical guideline data* will serve three primary functions: clinical decision support (selection of the most effective treatments for conditions), treatment process tracking (a detailed and standardized record of clinical interventions), and guideline variance tracking (the congruence between guideline-recommended treatment and actual treatment delivered). Even though *system guideline data* are essential for improving the quality of care and efficiency of operations, they are only in the earliest stages of development. *Performance indicators, report cards, and consumer outcome data* are critical for the accountability, quality improvement, and management of mental health systems. Although the field lacks uniform sets of performance indicators and outcome measures, there is an emerging consensus on the critical components for each and steady progress toward standardization.

## Data Availability

Not yet operational

## Relationship to other Standards

Decision Support 2000+ grew directly from the FN10 data standards (initiated in 1989 to collect data about clinical encounters) and the recommendations of the FN11 Workgroup (initiated to facilitate enrollment tracking, include encounter and performance indicator data, and address the special needs of children). The new Decision Support 2000+ (DS2000+) effort builds on and expands these MHSIP efforts by including the health status of the population, enrollment, encounter and outcome data, as well as system description and performance information. DS2000+ takes into account the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Standards for Electronic Transmission, the CMHS Uniform Reporting System (URS), and other mandated reporting such as ORYX.

## Future Plans

DS2000+ collaborators have completed a requirements analysis for the system and now are reaching out to the mental health community to help make it ready for implementation.





## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

A View from the Desert (gives the background/context of DS2000+): <http://www.mhsip.org/ds2000/desert.htm>

DS2000+ HIPAA Master Data Sets and Handbooks (detailed information on the data required for the relevant HIPAA transaction and the Handbooks provide the same information but in a simplified, more user-friendly format): <http://www.mhsip.org/DS2K+.htm>

DS 2000+ User's Guide: <http://www.mhsip.org/ds2000/usersguide.htm>

Initial requirements analysis for field review and comment is posted on: [www.mhsip.org](http://www.mhsip.org).

## **Web Site**

MHSIP Web site at: [www.mhsip.org](http://www.mhsip.org)

## **For More Information**

Olinda Gonzalez, Ph.D.

Division of State and Community Systems Development

SAMHSA/Center for Mental Health Services

1 Choke Cherry Road, Room 2-1087

Rockville, MD 20857

Telephone: (240) 276-1762

E-Mail: [Olinda.Gonzalez@samhsa.hhs.gov](mailto:Olinda.Gonzalez@samhsa.hhs.gov)

## **Reviewed**

No





## National Outcome Measures (NOMs)

### Sector

Behavioral Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics

### Purpose

A primary function of NOMs is the creation of a basic national data set to measure the performance of systems administered by state substance abuse and mental health agencies.

### Version

2005

### Year Current Version Was Adopted

2005

### Age of Standard

2004

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics

### Who Uses

NOMs data cover 10 domains for all discretionary and block/formula grant programs with client-level outcomes.

### Mandatory/Voluntary (and Authorization)

Unknown whether mandatory or voluntary reporting

Congress affirmed the need for this information in its reauthorization of SAMHSA under the Children's Health Act of 2000 (Public Law 106-310). In that Act, Congress called on SAMHSA to collaborate with the states and



other interested stakeholders to develop a plan “for creating more flexibility for states and accountability based on outcome and other performance measures” in both the Community Mental Health Services Block Grant program and the Substance Abuse Prevention and Treatment Block Grant program.

### **Estimate of Adoption**

As of March 2008, at least half of states are reporting on each NOMs domain (see <http://www.nationaloutcomemeasures.samhsa.gov/accomplishments.asp>)

### **Standards Development Process**

SAMHSA uses a consensus process to produce recommendations for NOMs.

### **Type of Content**

Outcome measures include: abstinence from drug use/alcohol abuse, decreased mental illness symptomatology, increased/retained employment or return to/stay in school, decreased criminal justice involvement, increased stability in family and living conditions, increased access to services (service capacity), increased retention in treatment—substance abuse, reduced utilization of psychiatric inpatient beds—mental health, increased social supports/social connectedness, client perception of care, cost effectiveness, use of evidence-based practices.

### **Unit of Collection**

Individual

### **Data Availability**

State profiles (combining NOMs data along with other SAMHSA data sources) are available at: [http://www.nationaloutcomemeasures.samhsa.gov/StateProfiles/index\\_2007.asp](http://www.nationaloutcomemeasures.samhsa.gov/StateProfiles/index_2007.asp)

### **Relationship to other Standards**

SAMHSA is using the Treatment Episode Data Set (TEDS) to collect treatment NOMs for the Substance Abuse Prevention and Treatment Block Grant, the National Survey on Drug Use and Health (NSDUH) to collect substance abuse prevention NOMs, and the Uniform Reporting System (URS) to collect NOMs for the Community Mental Health Services Block Grant.

NOMs staff are working toward full implementation of Transformation Accountability (TRAC) and the Center for Substance Abuse Prevention Service Accountability and Monitoring System (CSAMS). Efforts are being undertaken to examine ways to promote greater consistency across TRAC, CSAMS, and the Services Accountability Improvement System (SAIS).





## **Future Plans**

Looking forward from FY 2009 through FY 2011, SAMHSA will initiate the next set of activities:

- Continue to review the NOMs definitions and ensure that an appropriate balance is struck between the unique data collection needs of different programs/populations and the goals of streamlined and standardized data collection methods and definitions.
- Complete definition of developmental NOMs for both mental health and substance abuse programs.
- Help states develop the technical capacity to report all NOMs for mental health services and substance abuse prevention and treatment.
- Develop client-level NOMs to augment the information already obtained through the aggregate state data.
- Fully implement NOMs reporting systems (CSAM, TRAC, and SAIS) for all discretionary grants.
- Share program performance data across SAMHSA and with external partners, including providing regular feedback reports to grantees and states on their performance, along with identifying areas of improvement and identifying high performers who can provide technical assistance or mentoring to those who need assistance in improvements.
- Generate reports, which will include analyses of services to vulnerable populations including children, older adults, and cultural and linguistic minorities.

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

A detailed report on NOMs accomplishments is available at <http://nationaloutcomemeasures.samhsa.gov/accomplishments.asp>

## **Web Site**

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics Web site: <http://www.nationaloutcomemeasures.samhsa.gov/>

## **For More Information**

Terry L. Cline, Ph.D., Administrator  
Center for Mental Health Services  
1 Choke Cherry Road  
Rockville, MD 20857

## **Reviewed**

No







# National Reporting Program for Mental Health Statistics (NRP)

## Sector

Behavioral Health

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics

## Purpose

The National Reporting Program (NRP), a joint effort of local and national mental health organizations, collects and reports national, biennial statistical information on mental health services and the people who receive them. NRP is the only national source of information that focuses on services and clients from mental health organizations. It is operated collaboratively with the states, national organizations (National Association of State Mental Health Program Directors, National Association of Psychiatric Health Systems, and American Hospital Association), and local mental health organizations.

## Version

Unknown

## Year Current Version Was Adopted

Unknown

## Age of Standard

1840. The NRP is one of the longest continuous data collection efforts in American public health.

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics

## Who Uses

Local and state mental health organizations who report information about their staff, finances, and clients

## Mandatory/Voluntary (and Authorization)

The National Reporting Program is the only major human services data collection program that has functioned in a voluntary, collaborative manner over a long period.



NRP is authorized by Section 520 (b) (13) of the Public Health Service Act.

### **Estimate of Adoption**

The data include 6,500 mental health organizations and 13,000 service sites.

### **Standards Development Process**

Unknown

### **Type of Content**

State and local mental health organizations report data about their staff, finances, and clients.

### **Unit of Collection**

Individual client level and agency level

### **Data Availability**

Each year, NRP program staff respond directly to more than 2,000 requests for information and disseminate approximately 100,000 publications to members of the mental health field, researchers, federal agencies, media, and others.

### **Relationship to other Standards**

The following linkages are maintained with the fields of alcohol and drug abuse, general health, rehabilitation, and justice:

- Epidemiological data on mental disorders are coordinated with the National Center for Health Statistics, the National Institute of Mental Health, and the Office of Applied Studies within SAMHSA.
- Projects are underway with the Rehabilitation Services Administration in the Department of Education to study rehabilitation data on people with mental disabilities.
- Interagency agreements are in place with the National Center for Health Statistics to collect and analyze mental health information from the National Health Interview Survey for persons with disabilities and for children and their families.
- Survey data items have been included in a Department of Justice (DOJ) study of individuals on probation.
- Surveys of mental health services in state prisons and local jails were completed, and a survey of the juvenile justice system is underway in collaboration with DOJ.





## Future Plans

- NRP focuses on modernizing the data collection system, adapting to recent developments in managed care, and expanding coverage to provide a more comprehensive look at mental health services.
- NRP is looking at linkages among providers comprising systems of care outside traditional mental health settings and at models of care within these systems.
- NRP is testing the feasibility of surveying the consumer self-help system.

## Vendors Incorporating In Products

Unknown

## Key Documents and Reports

2002-2006 Center for Mental Health Services (CMHS) Uniform Reporting System Output Tables:

<http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics>

The results of National Reporting Program activities are showcased in a widely disseminated biennial publication on major mental health policy and statistical issues, Mental Health, United States:

<http://mentalhealth.samhsa.gov/publications/allpubs/SMA06-4195>

A comprehensive reference listing of organized mental health services available in the United States—arranged by state, city, and type of service—is made available through the Mental Health Directory. The 800-page directory identifies more than 6,500 mental health organizations and 13,000 service sites. An electronic version can be found on SAMHSA's National Mental Health Information Center Web site at

<http://mentalhealth.samhsa.gov>.

## Web Site

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics:

<http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/about.asp>

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Statistics, National Mental Health Information Center: <http://mentalhealth.samhsa.gov/publications/allpubs/KEN95-0025/default.asp>





**For More Information**

Terry L. Cline, Ph.D., Administrator  
Center for Mental Health Services  
1 Choke Cherry Road  
Rockville, MD 20857

**Reviewed**

No





## Treatment Episode Data Set (TEDS)

### Sector

Behavioral Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Office of Applied Studies

### Purpose

The Treatment Episode Data Set (TEDS) is an annual compilation of data on the number and characteristics of persons admitted to public and private substance abuse treatment programs receiving public funding.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

Admission data have been collected since 1989. In 2000 a discharge data set was added to allow TEDS to collect information on entire treatment episodes.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Office of Applied Studies

### Who Uses

TEDS comprises data that are routinely collected by states in monitoring their individual substance abuse treatment systems. In general, facilities reporting TEDS data are those that receive state alcohol and/or drug agency funds (including Federal Block Grant funds) for the provision of substance abuse treatment. However, differences in state systems of licensure, certification, accreditation, and disbursement of public funds affect the scope of facilities included in TEDS. Treatment facilities that are operated by private for-profit agencies, hospitals, and the state correctional system, if not licensed through the state substance abuse agency, may be excluded from TEDS. TEDS does not include data on facilities operated by federal agencies (the Bureau of Prisons, the Department of Defense, and the Veterans Administration).

**Mandatory/Voluntary (and Authorization)**

Within each state, treatment providers that receive any state agency funding, including the federal Substance Abuse Prevention and Treatment (SAPT) Block Grant monies, are expected to provide TEDS data for all clients admitted to treatment, regardless of the source of funding for individual clients. Participation is mandatory for publicly funded clients. Other clients participate on an optional basis.

The 1988 Comprehensive Alcohol Abuse, Drug Abuse, and Mental Health Amendments (P.L. 100-690) mandated federal data collection on clients receiving treatment for either alcohol or drug abuse. The TEDS data collection effort represents the federal response to this mandate.

**Estimate of Adoption**

The TEDS system includes records for 2 million substance abuse treatment admissions annually. While TEDS does not represent the total national demand for substance abuse treatment, it does comprise a significant proportion of all admissions to substance abuse treatment and includes those admissions that constitute a burden on public funds. In 1997, TEDS was estimated to represent 83 percent of all admissions to these facilities and was estimated to cover 67 percent of all known substance abuse treatment admissions, regardless of the source of funding for the treatment.

**Standards Development Process**

Unknown

**Type of Content**

Data collected include client demographics, client substance abuse problems, client mental health information, information on treatments received and source of client referral to treatment, and sources of payment for treatment.

**Unit of Collection**

TEDS is an admission-based system, and TEDS admissions do not represent individuals. An individual admitted to treatment twice within a calendar year would be counted as two admissions. Most states cannot, for reasons of confidentiality, identify clients with a unique ID assigned at the state level. Consequently, TEDS is unable to follow individual clients through a sequence of treatment episodes.

**Data Availability**

Data are available online at: <http://webapp.icpsr.umich.edu/cocoon/SAMHDA-SERIES/00056.xml>

**Relationship to other Standards**

SAMHSA is using the Treatment Episode Data Set (TEDS) to collect treatment National Outcome Measures (NOMs) for the Substance Abuse Prevention and Treatment Block Grant.





### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

A variety of reports produced by Substance Abuse and Mental Health Services Administration, Office of Applied Studies are available at:

<http://oas.samhsa.gov/dasis.htm#teds2>

Data can be accessed at: <http://webapp.icpsr.umich.edu/cocoon/SAMHDA-SERIES/00056.xml>

### **Web Site**

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Office of Applied Studies

### **For More Information**

Terry L. Cline, Ph.D., Administrator  
Center for Mental Health Services  
1 Choke Cherry Road  
Rockville, MD 20857

### **Reviewed**

No





## Uniform Reporting System (URS)

### Sector

Behavioral Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

### Purpose

The Uniform Reporting System (URS) is a federal reporting system used by state mental health agencies to compile and report annual data from each state as part of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services' Federal Community Mental Health Block Grant. Principal uses of the URS data are to track annual performance of all states and produce national aggregate totals on service utilization and outcome of state mental health systems at the national aggregate level.

### Version

Unknown

### Year Current Version was Adopted

Unknown

### Age of Standard

2001

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

### Who Uses

State Mental Health Agencies

### Mandatory/Voluntary (and Authorization)

Unknown



## **Estimate of Adoption**

In the December 2004 cycle, every state, the District of Columbia, and four territories submitted at least one table, and 11 states submitted data for every URS basic table.

## **Standards Development Process**

SAMHSA develops the reporting standards in consultation with state mental health agencies.

## **Type of Content**

The URS comprises a set of 21 tables developed by the federal government, in consultation with state mental health agencies, that compiles annual state-by-state and national aggregate information, including numbers and sociodemographic characteristics of persons served, the outcomes of care, use of selected evidence-based practices, client assessment of care, and insurance status. In addition, the URS tables compile information on the expenditures of state mental health agencies, local programs that receive CMHBG funds, uses of those funds, and general questions on the agency status.

## **Unit of Collection**

Individual and agency

## **Data Availability**

Unknown

## **Relationship to Other Standards**

SAMHSA is using URS tables to calculate 10 mental health National Outcome Measures (NOMs) for state/national reporting. They will also serve as a component of the DS2000+ framework to develop performance and outcome standards for the mental health field.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

2002 CMHS Uniform Reporting System Output Tables: <http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/URS2002.asp>

## **Web Site**

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration,





Center for Mental Health Services: [http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/about\\_urs2002.asp](http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/about_urs2002.asp)

**For More Information**

Terry L. Cline, Ph.D., Administrator  
Center for Mental Health Services  
1 Choke Cherry Road  
Rockville, MD 20857

**Reviewed**

No





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# CHILD AND FAMILY SERVICES





# Adoption and Foster Care Analysis and Reporting System (AFCARS)

## **Sector**

Child and Family Services

## **Type of Standard**

Reporting Requirements or Reporting Standards

## **Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families

## **Purpose**

The Adoption and Foster Care Analysis and Reporting System (AFCARS) collects case-level information on all children in foster care for whom the state child welfare agency has responsibility for placement, care, or supervision and on children who are adopted under the auspices of the state's public child welfare agency.

## **Version**

2000

## **Year Current Version Was Adopted**

2000

## **Age of Standard**

On September 27, 1990, HHS published proposed federal regulations to implement the data collection system. On December 22, 1993, the final rule implementing AFCARS appeared in the Federal Register.

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services/Administration for Children and Families

## **Who Uses**

States are required to submit all of their adoption and foster care data electronically to the Children's Bureau at the close of each of two semi-annual reporting periods. The first semi-annual reporting period extends from October 1 through March 31, the second from April 1 to September 30. States submit 37 adoption data elements and 66 foster care data elements.

## **Mandatory/Voluntary (and Authorization)**

The Adoption and Foster Care Analysis and Reporting System (AFCARS) is a federally mandated data collection system intended to provide case-specific information on all children covered by the protections of

**Title IV-B/E of the Social Security Act (Section**

427). Under the final AFCARS' rule, states are required to collect data on all adopted children who are placed by the state's child welfare agency or by private agencies under contract with the public child welfare agency. States are encouraged to report other private adoptions, not involving the public welfare agency, that are finalized in the state as well. In addition, states are required to collect data on all children in foster care for whom the state child welfare agency has responsibility for placement, care, or supervision.

**Estimate of Adoption**

The mandatory nature of reporting means that compliance is high among states.

**Standards Development Process**

Unknown

**Type of Content**

The National Data Archive on Child Abuse and Neglect distributes two data files for each fiscal year; one file contains adoption data and the other foster care data. Each adoption data file contains 37 elements that provide information on the adopted child's gender, race, birth date, ethnicity, and prior relationship with the adoptive parents. The date the adoption was finalized, as well as dates parental rights were terminated, characteristics of birth and adoptive parents, and whether the child was placed from within the United States or from another country are also captured. The foster care data files contain 66 elements that provide information on child demographics including gender, birth date, race, and ethnicity. Information about the number of previous stays in foster care, service goals, availability for adoption, dates of removal and discharge, funding sources, and the biological and foster parents is also included in the foster care files.

**Unit of Collection**

Individual (child)

**Data Availability**

AFCARS tables and other reports summarizing the AFCARS data are available from the Children's Bureau Web site: <http://www.acf.hhs.gov/programs/cb>.

**Relationship to other Standards**

The SACWIS functions as a "case management" system that serves as the electronic case file for children and families served by the states' child welfare programs. One of the reports produced from SACWIS is the AFCARS data sent to the Administration for Children and Families. In order to qualify for SACWIS funding, states' systems must, among other things, meet the AFCARS requirements in 45 CFR 1355.40. States that develop a SACWIS with federal funding must not collect the AFCARS data from a separate information system once the SACWIS is operational.





## **Future Plans**

The Children's Bureau (Administration on Children, Youth, and Families, Department of Health and Human Services) published a notice of proposed rulemaking (NPRM) in the Federal Register on Friday, January 11, 2008. The NPRM proposes numerous improvements to AFCARS data, including changes to the reporting populations, data structure, elements, compliance determination, and penalty provisions. The Bureau wants child and family identifiers over time, no matter where the child is in the state so that a child's data across report periods may be linked with other family members and to the National Youth in Transition Database. The Children's Bureau also wants to link data to the National Youth in Transition Database.

## **Vendors Incorporating In Products**

The Children's Bureau has made software utilities available for download to assist states in their reporting.

## **Key Documents and Reports**

Adoption and Foster Care Statistics published by the Administration for Children and Families is available at: [http://www.acf.hhs.gov/programs/cb/stats\\_research/index.htm#afcars](http://www.acf.hhs.gov/programs/cb/stats_research/index.htm#afcars)

Multi-Year User's Guide (Data Codebook) 2000-present: [http://www.ndacan.cornell.edu/NDACAN/Datasets/UserGuidePDFs/AFCARS\\_Guide\\_2000-Present.pdf](http://www.ndacan.cornell.edu/NDACAN/Datasets/UserGuidePDFs/AFCARS_Guide_2000-Present.pdf)

The data set is available through the National Data Archive on Child Abuse and Neglect at Cornell University: <http://www.ndacan.cornell.edu>.

Beebe Hall - FLDC

Cornell University

Ithaca, NY 14853

Telephone: (607) 255-7799

Facsimile: (607) 255-8562

E-Mail: [NDACAN@cornell.edu](mailto:NDACAN@cornell.edu)

## **Web Site**

U.S. Health and Human Services Children's Bureau Web site: <http://www.acf.hhs.gov/programs/cb>

National Resource Center for Child Welfare Data and Technology Web site: <http://www.nrccwdt.org>



### **For More Information**

John Hargrove  
Children's Bureau  
Administration on Children, Youth, and Families  
330 C Street SW  
Washington, DC 20204  
E-mail: [john.hargrove@acf.hhs.gov](mailto:john.hargrove@acf.hhs.gov)

### **Reviewed**

No





# Child Support and Court/Judicial Message Exchange Data Model

## **Sector**

Child and Family Services  
Criminal Justice/Courts

## **Type of Standard**

Data Interoperability Standard

## **Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement and Conference of Chief Justices within the National Center for State Courts

## **Purpose**

Child Support and Court/Judicial Message Exchange Data Model provides data standards for the Child Support community to facilitate an automated data exchange with the courts/judiciary.

## **Version and Year of Adoption**

2008

## **Age of Standard**

Endorsed by the Federal Office of Child Support Enforcement Oversight Board and by the Conference of Chief Justices within the National Center for State Courts in 2008

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement

## **Who Uses**

State Child Support Enforcement agencies and courts

## **Mandatory/Voluntary (and Authorization)**

While this exchange is not mandated, adoption highly recommend this since it meets the business needs to provide a common structure for automated exchange of information and documents between participating child support enforcement agencies and courts.

## **Estimate of Adoption**

A proof of concept is under development by Colorado, which will provide the courts and CSE communities with valuable insight to the implementation of the data exchanges.





## **Standards Development Process**

The Federal Office of Child Support Enforcement Data Standards Oversight Board endorsed the Child Support and Court/Judicial Message Exchange Data Model, and vetting through the National Center for State Courts Joint Technology Committee

## **Type of Content**

Case data, obligor/person data, obligee/person data, child data, financial data, and event data

## **Unit of Collection**

Family

## **Data Availability**

A proof of concept using these standards is under development by Colorado, which will provide the courts and CSE communities with valuable insight to the implementation of the data exchanges.

## **Relationship to other Standards**

The new data standards were developed through integration of the National Information Exchange Model (NIEM) and CSE standards. NIEM is a culmination of the Global Justice XML Data Model (GJXDM) and Legal XML, which pioneered efforts at an exchange model.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

National Judicial-Child Support Task Force business case templates to support the states and courts in their electronic exchange of information: <http://www.acf.hhs.gov/programs/cse/pol/DCL/2008/dcl-08-01.htm>

## **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement: <http://www.acf.hhs.gov/programs/cse>

Joint Technology Committee of the National Center for State Courts: [http://www.ncsconline.org/d\\_tech/gjxdm/IEPD.asp#ChildSupport](http://www.ncsconline.org/d_tech/gjxdm/IEPD.asp#ChildSupport)





### **For More Information**

Richard Ordowich  
Coordinator for Data Quality/Data Standards  
Office of Child Support Enforcement  
U.S. Department of Health and Human Services  
Telephone: (202) 260-5495  
E-mail: [richard.ordowich@acf.hhs.gov](mailto:richard.ordowich@acf.hhs.gov)

### **Reviewed**

No



## Head Start Program Information Report (PIR)

### Sector

Child and Family Services

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Head Start

### Purpose

The Head Start Program Information Report collects comprehensive data on the services, staff, children, and families served by Head Start and Early Head Start programs.

### Version and Year of Adoption

2008

### Age of Standard

Unknown

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Head Start

### Who Uses

All Head Start and Early Head Start programs

### Mandatory/Voluntary (and Authorization)

All programs are required to submit a PIR for each year in which they provide services to children and families.

According to federal mandates, all Head Start and Early Head Start programs are required to report data on an annual basis. Head Start Performance Standards are under the authority for the final rule in sections 641(a) and (d), 642(b) and (d), 644(a) and (c), and 645(h)(2) of the Head Start Act, as amended (42 U.S.C. 9801 et. Seq.).

### Estimate of Adoption

Given that reporting is mandatory, compliance is expected to be high.





## **Standards Development Process**

Unknown

## **Type of Content**

The enrollment report describes the program options provided by Head Start and Early Head Start programs and provides demographic information on the children and pregnant women served. Additional information collected in the PIR enrollment report includes funded and actual enrollment, eligibility, and turnover of enrollees. The family services report provides information on Head Start and Early Head Start family characteristics, including the number and types of families served, employment, education level, and the types of services the programs provide in response to family needs.

## **Unit of Collection**

Child or family, but aggregated with others at the program level

## **Data Availability**

Data are only available as aggregate. Requests to use the data should be e-mailed to the Office of Head Start, where it will be reviewed and approved before data access is granted.

## **Relationship to other Standards**

None

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Grantees may use online reporting or software products that generate the mandatory reports.

## **Key Documents and Reports**

Research about Head Start and Early Head Start, created by the Office of Planning, Research, and Evaluation is available at: <http://www.acf.hhs.gov/programs/ohs/research/index.html>



### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Head Start: <http://www.acf.hhs.gov/programs/ohs/index.html>

### **For More Information**

Office of Head Start  
Office of Program Management and Operations  
370 L'Enfant Plaza SW  
Washington, DC 20447  
Telephone: (202) 205-8396

### **Reviewed**

No





# National Child Abuse and Neglect Data System (NCANDS)

## **Sector**

Child and Family Services

## **Type of Standard**

Reporting Requirements or Reporting Standards

## **Sponsor**

U.S. Department of Health and Human Services, Administration on Children and Families, Children's Bureau

## **Purpose**

The National Child Abuse and Neglect Data System (NCANDS) is a federally sponsored national data collection effort created for the purpose of tracking the volume and nature of child maltreatment reporting each year within the United States.

## **Version**

Unknown

## **Year Current Version Was Adopted**

Unknown

## **Age of Standard**

1990

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration on Children and Families, Children's Bureau

## **Who Uses**

States extract case-level data from their child welfare information systems for submission to NCANDS. All reports reaching a disposition date in a given year are mapped to the NCANDS data elements and included in the submission.

## **Mandatory/Voluntary (and Authorization)**

The National Child Abuse and Neglect Data System (NCANDS) is a voluntary national data collection and analysis system created in response to the requirements of the Child Abuse Prevention and Treatment Act (Public Law 93-247) as amended.



## **Estimate of Adoption**

Forty-nine states, the District of Columbia, and Puerto Rico submitted data to the NCANDS Child File for FFY 2006. The only state that did not submit data was Maryland.

## **Standards Development Process**

Unknown

## **Type of Content**

The NCANDS consists of two components:

- The Summary Data Component is a compilation of key aggregate child abuse and neglect statistics from all states, including data on reports, investigations, victims, and perpetrators.
- The Detailed Case Data Component is a compilation of case-level information from those child protective services agencies able to provide electronic child abuse and neglect records. This file consists of two data files from each participating state. One of the two state files contains 14 variables and includes characteristics of all children included in a report of alleged maltreatment. Characteristics of the report such as the source and disposition are also included in this file. The second file contains 62 variables. Only children identified as victims are included. A child is classified as a victim and included in this file if maltreatment is substantiated or indicated. In addition to basic information concerning the report and the child, this child victim's file also contains information about the type of maltreatment, the support services provided to the family, and any special problems that were identified for the child, caretaker, or family. Neither of the files contains data on the alleged perpetrators, and reports of child fatalities have also been excluded from both files.

## **Unit of Collection**

The unit of observation in the Child File includes report-level data for all children who have received a disposition of an investigation or assessment of allegations of maltreatment during the reporting year. Each child on a report gets a separate data record, referred to as a "report-child pair." As a child may be in the data file multiple times, there is a unique identifier assigned to each child.

## **Data Availability**

NCANDS has become the primary source of national information on abused and neglected children reported to state child protective service agencies. Findings from the NCANDS data are published by the Children's Bureau each year in its Child Maltreatment report series.

## **Relationship to other Standards**

NCANDS data have been incorporated into the Child and Family Services Reviews (CFSR), which ensures





conformity with state plan requirements in titles IV-B and IV-E of the Social Security Act. The NCANDS data also are used in the Program Assessment Rating Tool (PART), which is “a systematic method of assessing the performance of program activities across the federal government.” Children’s Bureau programs funded under the CAPTA Basic State Grant and the Community-Based Child Abuse Prevention (CBCAP) State Grants use data from NCANDS as a component of their PART assessments.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

NCANDS Summary Data Component Data Elements: <http://www.acf.hhs.gov/programs/cb/pubs/congress/ncands.htm>

NCANDS survey instruments for the Summary Data Component and the Detailed Case Data Component, as well as the glossary of terms: <http://www.acf.hhs.gov/programs/cb/systems/ncands/survey.htm>

Restricted usage files of state report-level data are available for researchers from the National Data Archive on Child Abuse and Neglect at [www.ndacan.cornell.edu](http://www.ndacan.cornell.edu)

### **Web Site**

U.S. Health and Human Services Children’s Bureau Web site: <http://www.acf.hhs.gov/programs/cb/systems/index.htm#ncands>

### **For More Information**

John Hargrove  
Children’s Bureau  
Administration on Children, Youth and Families  
330 C Street SW  
Washington, DC 20204  
E-mail: [john.hargrove@acf.hhs.gov](mailto:john.hargrove@acf.hhs.gov)

### **Reviewed**

No









## **National Vital Statistics System: Mortality (NVSS-M)**

### **Sector**

Child and Family Services  
Public Health

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### **Purpose**

The National Vital Statistics System Mortality (NVSS-M) data set is generated from death certificate information collected through the National Vital Statistics System, an intergovernmental collaboration between NCHS and the 50 states, 2 cities, and 5 territories. The NVSS-M data serve as the primary source of information on demographic, geographic, and cause-of-death information among persons dying in a given year. Data are available on an annual basis.

### **Version**

Beginning with 1989, revised standard certificates replaced the 1978 versions; implementation of the next revision, for 2003, is being phased in by the states.

### **Year Current Version Was Adopted**

2003

### **Age of Standard**

The data system began in 1880, but not all states participated before 1933. Coverage for deaths has been complete since 1933.

### **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

**Who Uses**

Administrative records (death certificates) completed by funeral directors, physicians, medical examiners, and coroners are filed with state vital statistics offices; selected statistical information is forwarded to NCHS to be merged into a national statistical file. Demographic information on the death certificate is provided by the funeral director and is based on information supplied by an informant. Medical certification of cause of death is provided by a physician, medical examiner, or coroner.

**Mandatory/Voluntary (and Authorization)**

Mandatory

**Estimate of Adoption**

NVSS mortality files include data for the 50 states, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Marianas. All deaths occurring in those areas are included (approximately 2.3 to 2.4 million annually).

**Standards Development Process**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for nationwide use through cooperative activities of the jurisdictions and NCHS.

**Type of Content**

Year of death, place of decedent's residence, place death occurred, age at death, day of week and month of death, Hispanic origin, race, marital status (beginning in 1979), place of birth, gender, underlying and multiple causes of death for all states, injury at work (beginning in 1993), hospital and patient status, and educational attainment (beginning in 1989) for selected states.

**Unit of Collection**

Individual

**Data Availability**

Public use data sets are available at no cost.

**Relationship to other Standards**

NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI); Medicare enrollment and claims data from the Centers for Medicare and Medicaid Services (CMS); and Retirement, Survivor, and Disability Insurance (RSDI) and Supplemental Security Income (SSI) benefit data from the Social Security Administration (SSA). See: [http://www.cdc.gov/nchs/data\\_access/data\\_linkage\\_activities.htm](http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm)





Specifically for mortality, NCHS has developed a record linkage program designed to maximize the scientific value of the Center's population-based surveys. NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI). Linkage of the NCHS survey participants with the NDI provides the opportunity to conduct a vast array of outcome studies designed to investigate the association of a wide variety of health factors with mortality. NCHS surveys linked with mortality data:

- National Health Interview Survey (NHIS)
- NHANES I Epidemiologic Follow-up Study (NHEFS) Linked Mortality File
- Second National Health and Nutrition Examination Survey (NHANES II)
- Third National Health and Nutrition Examination Survey (NHANES III)
- The Second Longitudinal Study of Aging (LSOA II)
- 1985 National Nursing Home Survey

### **Future Plans**

CDC's National Center for Health Statistics is working with state partners represented by the National Association of Public Health Statistics and Information Systems and the Social Security Administration to fundamentally re-engineer the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates. The primary objective is to improve the timeliness, quality, and sustainability of the decentralized vital statistics system, along with collection of the revised and new content of the 2003 certificates, by adopting technologically sophisticated, yet cost-effective, model IT systems based on nationally developed standards and models. Information on the re-engineering activities and technical documents are available at the NAPHSIS Web site, as well as at the NCHS certificate revision Web site.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Latest Routine Reports and Associated Releases: <http://www.cdc.gov/nchs/deaths.htm>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics: <http://www.cdc.gov/nchs/nvss.htm>



**For More Information**

Edward J. Sondik, Ph.D.

Director

National Center for Health Statistics

3311 Toledo Road

Hyattsville, MD 20782

Telephone: (800) 232-4636

**Reviewed**

No





## National Vital Statistics System: Natality (NVSS-N)

### Sector

Child and Family Services  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### Purpose

The National Vital Statistics System Natality (NVSS-N) comprises records of all documented births occurring within the United States.

### Version

2003

### Year Current Version Was Adopted

2003

### Age of Standard

The national birth registration system was established in 1915. Not all states participated before 1933. Coverage for births has been complete since 1933.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### Who Uses

Administrative records (birth certificates) completed by physicians and midwives are filed with state vital statistics offices; selected statistical information is forwarded to NCHS to be merged into a national statistical file. Beginning in 1989, revised standard certificates replaced the 1978 versions; implementation of the next scheduled revision, for 2003, is being phased in by the states. Demographic information on the birth certificate is provided by the informant, usually the mother; maternal and infant health information is provided by the physician.

**Mandatory/Voluntary (and Authorization)**

In the United States, state laws require birth certificates to be completed for all births, and federal law mandates national collection and publication of births and other vital statistics data.

**Estimate of Adoption**

NVSS natality files include data for the 50 states, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Marianas. All births occurring in those areas are included (approximately 4 million annually).

**Standards Development Process**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the states and NCHS.

**Type of Content**

Demographic items collected include year of birth, place of mother's residence, place birth occurred, age of mother and of father, day of week and month of birth, Hispanic origin and race of mother and of father, marital status of mother, place of birth (that is, state or country) of mother and of father, educational attainment of mother and of father, sex of child, and live-birth order. Maternal and infant health information is collected, including month prenatal care began, number of prenatal visits, medical risk factors, tobacco use, alcohol use, maternal weight gain, obstetric procedures, attendant at birth, method of delivery, place of delivery, complications of labor and/or delivery, period of gestation, birthweight, Apgar score, abnormal conditions of newborn, congenital anomalies, and plurality.

**Unit of Collection**

Individual

**Data Availability**

Information on the Public Use Files and instructions for obtaining files can be located at [http://www.cdc.gov/nchs/products/elec\\_prods/subject/natality.htm](http://www.cdc.gov/nchs/products/elec_prods/subject/natality.htm), or by contacting [births@cdc.gov](mailto:births@cdc.gov).

**Relationship to other Standards**

NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI); Medicare enrollment and claims data from the Centers for Medicare and Medicaid Services (CMS); and Retirement, Survivor, and Disability Insurance (RSDI) and Supplemental Security Income (SSI) benefit data from the Social Security Administration (SSA). See: [http://www.cdc.gov/nchs/data\\_access/data\\_linkage\\_activities.htm](http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm)





### **Future Plans**

CDC's National Center for Health Statistics is working with state partners represented by the National Association of Public Health Statistics and Information Systems and the Social Security Administration to fundamentally re-engineer the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates. The primary objective is to improve the timeliness, quality, and sustainability of the decentralized vital statistics system, along with collection of the revised and new content of the 2003 certificates, by adopting technologically sophisticated, yet cost-effective, model IT systems based on nationally developed standards and models. Information on the re-engineering activities and technical documents are available at the NAPHSIS Web site, as well as at the NCHS certificate revision Web site.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Birth data: <http://www.cdc.gov/nchs/births.htm>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics: <http://www.cdc.gov/nchs/nvss.htm>

### **For More Information**

Edward J. Sondik, Ph.D.

Director

National Center for Health Statistics

3311 Toledo Road

Hyattsville, MD 20782

Telephone: (800) 232-4636

### **Reviewed**

No







## National Youth in Transition Database (NYTD)

### **Sector**

Child and Family Services

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families

### **Purpose**

The National Youth in Transition Database (NYTD) collects case-level information on youth in care including the services paid for, or provided by, the state agencies that administer the Chafee Foster Care Independence Program (CFCIP) as well as the outcome information on youth who are in, or who have aged out of, foster care.

### **Version**

2008

### **Year Current Version Was Adopted**

2008

### **Age of Standard**

The Administration for Children and Families published a proposed rule in the Federal Register on July 14, 2006, and a final rule on February 26, 2008.

### **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration for Children and Families

### **Who Uses**

States

### **Mandatory/Voluntary (and Authorization)**

The rule that established the NYTD requires states to engage in two data collection activities. First, the state is to collect information on each youth who receives independent living services paid for, or provided by, the state and transmit this information to the Administration for Children and Families biannually. Second, the state is to collect demographic and outcome information on certain youth in foster care whom the state will follow over



time to collect additional outcome information. This information will allow the Administration for Children and Families to track which independent living services states provide and assess the collective outcomes of youth.

Public Law 106-169 established the John H. Chafee Foster Care Independence Program (CFCIP) at section 477 of the Social Security Act, providing states with flexible funding to carry out programs that assist youth in making the transition from foster care to self-sufficiency. The law requires the Administration for Children and Families to develop a data collection system to track the independent living services states provide to youth and develop outcome measures that may be used to assess states' performance in operating their independent living programs. The law requires the Administration for Children and Families to impose a penalty of between 1 and 5 percent of the state's annual allotment on any state that fails to comply with the reporting requirements.

### **Estimate of Adoption**

States will have until October 1, 2010, to implement the rule, at which time they must begin to collect data. The first submission of data to the Administration for Children and Families will be due no later than May 15, 2011.

### **Standards Development Process**

Unknown

### **Type of Content**

The final rule requires that states report to the Administration for Children and Families the independent living services and supports they provide to all youth in 11 broad categories: independent living needs assessment; academic support; post-secondary educational support; career preparation; employment programs or vocational training; budget and financial management; housing education and home management training; health education and risk prevention; family support and healthy marriage education; mentoring; and supervised independent living. States will also report financial assistance they provide including assistance for education, room and board, and other aid. States will survey youth regarding six outcomes: financial self-sufficiency, experience with homelessness, educational attainment, positive connections with adults, high-risk behavior, and access to health insurance.

States are to collect the outcomes information by conducting a survey of youth in foster care on or around their 17th birthday, also referred to as the baseline population. States will track these youth as they age and conduct a new outcome survey on or around the youth's 19th birthday, and again on or around the youth's 21st birthday, also referred to as the follow-up population. States will collect outcomes information on these older youth after they leave the state's foster care system, regardless of whether they are still receiving independent living services from the state when they are 19 or 21 years old. Depending on the size of the state's foster care youth population, some states may conduct a random sample of the baseline population of the 17-year-olds to participate in the outcomes survey so that they can follow a smaller group of youth as they age. All states will collect and report outcome information on a new cohort of youth every 3 years.





### **Unit of Collection**

Individual

### **Data Availability**

Not yet available

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Children's Bureau Presentation on NYTD at:

<http://www.acf.hhs.gov/programs/cb/systems/nytd/presentation.pdf>

The Children's Bureau Web site: [http://www.acf.hhs.gov/programs/cb/laws\\_policies/policy/im/2008/im0801.pdf](http://www.acf.hhs.gov/programs/cb/laws_policies/policy/im/2008/im0801.pdf)

Children's Bureau Resource Partners:

National Resource Center for Child Welfare Data and Technology: <http://www.nrccwdt.org>

National Child Welfare Resource Center for Youth Development: <http://www.nrcys.ou.edu/yd>

### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families Web site: [http://www.acf.hhs.gov/programs/cb/systems/nytd/about\\_nytd.htm](http://www.acf.hhs.gov/programs/cb/systems/nytd/about_nytd.htm)



**For More Information**

Gail Collins, Director of the Division of Program Implementation  
Children's Bureau  
Administration on Children, Youth, and Families  
U.S. Department of Health and Human Services, Switzer Building  
330 C Street SW - Room 2058-B  
Washington, DC 20447  
Telephone: (202) 205-8552  
Facsimile: (202) 205-8221  
E-mail: [gail.collins@acf.hhs.gov](mailto:gail.collins@acf.hhs.gov)

**Reviewed**

No





## **Pediatric Nutrition Surveillance System (PedNSS)**

### **Sector**

Child and Family Services  
Food and Nutrition  
Public Health

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### **Purpose**

The Pediatric Nutrition Surveillance System (PedNSS) is a child-based public health surveillance system that monitors the nutrition of low-income children in federally funded maternal and child health programs.

### **Version**

Unknown

### **Year Current Version Was Adopted**

Unknown

### **Age of Standard**

In the late 1960s, the United States Ten-State Nutrition Survey characterized the nutritional status of children from low-income families as being less than satisfactory. The findings generated concern about the nutritional status of low-income populations in the United States, especially children. Specifically, calories, calcium, iron, and vitamins A and C were less likely to be consumed in adequate amounts by low-income black and Hispanic children. In response, CDC began working with five states (Arizona, Kentucky, Louisiana, Tennessee, and Washington) in 1973 to develop a system for continuous monitoring of the nutritional status of selected high-risk population groups.

### **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

**Who Uses**

Federally funded health clinics serving low-income children participate on a voluntary basis and report data to state-level agencies, which in turn submit data to CDC. The majority of PedNSS records (85.4 percent) are from the WIC Program. The figure below shows the distribution of records received from WIC, EPSDT, MCH and other programs.

**Mandatory/Voluntary (and Authorization)**

PedNSS is a voluntary surveillance system. In 2007, 44 states, 1 U.S. Territory, 5 Indian Tribal Organizations, and the District of Columbia contributed data representing nearly 8 million under 5 years of age.

**Estimate of Adoption**

In 2004, a total of 48 contributors including 40 states, the District of Columbia, Puerto Rico, and 7 tribal governments participated in PedNSS.

**Standards Development Process**

Unknown

**Type of Content**

Demographic data collected by PedNSS include race or ethnicity, sex, migrant status, household income (where indicated), and zip code. Data collected to assess nutritional status include weight, length/height, and hemoglobin or hematocrit measurements. Weight, stature, and length are commonly used to assess the size and growth of children. Data on birthweight and breastfeeding status are collected on children from birth to 2 years of age. Health risk behavior data includes tv/video viewing and household smoking.

**Unit of Collection**

Individual (unique child records)

**Data Availability**

National data set is not available to the public, but published tables and reports are available.

**Relationship to other Standards**

PedNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program; and
- Title V Maternal and Child Health Program (MCH).





A majority of the data are from the WIC program that serves children up to age 5.

An important use of the PedNSS data is monitoring the Healthy People 2010 objectives.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

PedNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pednss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pednss_users_guide/index.htm)

2006 PedNSS Summary Report: [http://www.cdc.gov/pednss/pdfs/PedNSS\\_2006.pdf](http://www.cdc.gov/pednss/pdfs/PedNSS_2006.pdf)

National PedNSS data tables can be accessed through the following Web site:

<http://www.cdc.gov/pednss>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):

<http://www.cdc.gov/pednss/index.htm>

### **For More Information**

Division of Nutrition, Physical Activity and Obesity

National Center for Chronic Disease Prevention and Health Promotion

Centers for Disease Control and Prevention

4770 Buford Highway NE

Mail Stop K-25

Atlanta, GA 30341-3717

Telephone: (770) 488-5702

### **Reviewed**

No







## Pregnancy Nutrition Surveillance System (PNSS)

### Sector

Child and Family Services

Food and Nutrition

Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Purpose

The Pregnancy Nutrition Surveillance System (PNSS) monitors risk factors associated with infant mortality and poor birth outcomes among low-income pregnant women who participate in federally funded public health programs including Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); and Title V, the Maternal and Child Health Program (MCH).

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

PNSS has been in existence since 1979 when representatives from five states (Arizona, California, Kentucky, Louisiana, and Oregon) began working with CDC to develop a system for monitoring the prevalence of nutrition problems and behavioral risk factors related to mortality and low birthweight among infants born to high-risk pregnant women.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Who Uses

Federally funded health clinics serving pregnant women participate on a voluntary basis and report data to state-level agencies, which in turn submit the data to CDC. These data are combined for annual reporting. Approximately 99 percent of PNSS data comes from the WIC Program.



## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

In 2006, 26 states, 1 U.S. territory and 5 Indian Tribal Organizations contributed data representing approximately 1.1 million women. The number of surveillance records has increased from approximately 10,000 in 1979 to over 700,000 in 2002.

## **Standards Development Process**

Unknown

## **Type of Content**

Data on maternal health indicators include pre-pregnancy weight status, maternal weight gain, parity, interpregnancy intervals, anemia, diabetes, and hypertension during pregnancy. Data on maternal behavioral indicators include medical care, WIC enrollment, multivitamin consumption, smoking, and drinking.

## **Unit of Collection**

Individual

## **Data Availability**

Data tables can be accessed through the following Web site:

[http://www.cdc.gov/pednss/pnss\\_tables/index.htm](http://www.cdc.gov/pednss/pnss_tables/index.htm)

## **Relationship to Other Standards**

PNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Title V Maternal and Child Health Program (MCH)

A majority of the data are from the WIC program that serves pregnant, breastfeeding, and postpartum women.

An important use of the PNSS data is monitoring the Healthy People 2010 objectives.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**





Unknown

### **Key Documents and Reports**

PNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pnss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pnss_users_guide/index.htm)

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):  
<http://www.cdc.gov/pednss/index.htm>

### **For More Information**

Division of Nutrition, Physical Activity, and Obesity  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
4770 Buford Highway NE  
Mail Stop K-25  
Atlanta, GA 30341-3717  
Telephone: (770) 488-5702

### **Reviewed**

No





# **Runaway and Homeless Youth Management Information System (RHYMIS)**

## **Sector**

Child and Family Services

## **Type of Standard**

Reporting Requirements or Reporting Standards

## **Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families

## **Purpose**

The Runaway and Homeless Youth Management Information System (RHYMIS) was designed to provide comprehensive information on youth served, issues that affect them, and services provided for Runaway and Homeless Youth programs funded by the Family and Youth Services Bureau (FYSB). (RHYMIS) is an automated information tool designed to capture data on the runaway and homeless youth being served by Family and Youth Services Bureau's (FYSB) Basic Center Program and Transitional Living Program for Older Homeless Youth. RHYMIS also captures information on the contacts made by the Street Outreach Program grantees and the brief service contacts made with youth or families calling the FYSB programs.

## **Version**

In 2008, NEORHYMIS Version 2.1 was released with several new fields for Basic Center Program data about prevention, Transitional Living Program for Older Homeless Youth wait list or non-residential services, and Street Outreach Program shelter entries.

## **Year Current Version Was Adopted**

2008

## **Age of Standard**

1974

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration for Children and Families

## **Who Uses**

Grantees of Family and Youth Services Bureau report data. Current grantees must report on the profile of the youth and families they serve and provide an overview of the services which they deliver under their grant



programs. In order to assist grantees in their reporting responsibilities, FYSB funded the development of a Runaway and Homeless Youth Management Information System (RHYMIS).

### **Mandatory/Voluntary (and Authorization)**

Mandatory for Family and Youth Services Bureau grantees

Authorization for RHYMIS falls under the Runaway and Homeless Youth Act as Reauthorized (2003) by 42 U.S.C. 5701.

### **Estimate of Adoption**

All data beginning in FY 2002 is based on virtually a 100 percent response rate.

### **Standards Development Process**

Changes are made in consultation with grantees, advocates, experts, and regional staff. Publication of Federal Register Notice of Information Collection is required each major change. Input from the public is considered and often incorporated. Changes must be negotiated with U.S. Office of Management and Budget/Office of Information and Regulatory Affairs for approval pursuant to the Paperwork Reduction Act.

### **Type of Content**

Demographics, critical issues, referral source, services provided, living situations at entry and exit, and so forth on each youth in Basic Center Program and Transitional Living Program for Older Homeless Youth program

### **Unit of Collection**

Individual

### **Data Availability**

RHYMIS is collected on a semi-annual basis. Due dates are April 15th and October 15th. Data are released for a full fiscal year. There are some limitations on use involving privacy issues.

### **Relationship to other Standards**

There is full or partial consistency with approximately 33 percent of data elements/definitions between NEORHYMIS and HUD Homelessness Management Information System (HMIS).

### **Future Plans**

Greater consistency with HMIS is under intensive discussion with HUD. A “hybrid” system preserving essential elements of both is under development. Variables not likely to be added or removed for several years.





### **Vendors Incorporating In Products**

Program staff utilize desktop software (NEO-RHYMIS) provided by FYSB to complete an intake and exit form for each youth serviced by the program.

### **Key Documents and Reports**

NEO-RHYMIS Web site: <https://extranet.acf.hhs.gov/rhymis>

### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families:  
<http://www.acf.hhs.gov/programs/fysb/content/youthdivision/index.htm>

### **For More Information**

Stan Chappell, Director of Research and Evaluation,  
Family and Youth Services Bureau  
Administration for Children and Families  
U.S. Department of Health and Human Services  
1250 Maryland Avenue SW  
Washington, DC 20024  
Telephone: (202) 205-8496  
Facsimile: (202) 205-9535  
E-mail: [schappell@acf.hhs.gov](mailto:schappell@acf.hhs.gov)

### **Reviewed**

Yes







# Statewide Automated Child Welfare Information Systems (SACWIS)

**Sector**

Child and Family Services

**Type of Standard**

Reporting Requirements or Reporting Standards

**Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families

**Purpose**

The Statewide Automated Child Welfare Information System (SACWIS) is a comprehensive automated case management tool that supports social workers' foster care and adoptions assistance case management practice.

**Version**

Unknown

**Year Current Version Was Adopted**

Unknown

**Age of Standard**

1993

**Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration for Children and Families

**Who Uses**

States

**Mandatory/Voluntary (and Authorization)**

Voluntary—states receive Federal Financial Participation (FFP) for the development of a system through the Omnibus Reconciliation Act of 1993. If a state elects to implement a SACWIS, the system is expected to be a comprehensive automated case management tool that meets the needs of all staff (including social workers and their supervisors, whether employed by the state, county, or contracted private providers) involved in foster care and adoptions assistance case management. SACWIS funding is available for development, implementation, and operational costs. In exchange for the additional funding provided to a state that elects to implement a SACWIS, the state must agree that the SACWIS will be the sole case management automation tool used by all



public and private social workers responsible for case management activities. Furthermore, staff are expected to enter all case management information into SACWIS so it holds a state's "official case record"—a complete, current, accurate, and unified case management history on all children and families served by the Title IV-B/IV-E state agency. SACWIS systems must also collect and manage the information necessary to facilitate the delivery of child welfare support services, including family support and family preservation.

The genesis of focused federal support for statewide automated child welfare information systems (SACWIS) sprang from Title XIII, Section 13713., ENHANCED MATCH FOR AUTOMATED DATA SYSTEMS, of the Omnibus Budget Reconciliation Act (OBRA) of 1993 (Public Law 103-66), enacted on August 19, 1993. That legislation provided states with the opportunity to obtain 75 percent enhanced funding through the Title IV-E program of the Social Security Act to plan, design, develop, and implement a SACWIS. This legislation made the enhanced funding available for federal fiscal years 1993 through 1996. Title V, Section 502 of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA - Public Law 104-193), enacted on August 22, 1996, extended the SACWIS enhanced funding through federal fiscal year 1997. Additionally, the legislation provided an enhanced SACWIS cost allocation to states so that Title IV-E would absorb all SACWIS costs for foster and adopted children, without regard to their Title IV-E eligibility.

Subsequent to the passage of OBRA 1993, the Administration for Children and Families promulgated the Departmental regulations at 45 CFR 1355.50 - 1355.57, issued on December 22, 1993. These regulations implemented sections 474(a)(3)(C) and (D) of Title IV-E of the Social Security Act which were added as a result of P.L. 103-66.

### **Estimate of Adoption**

Currently, most states and the District of Columbia are at some stage of SACWIS planning, development, implementation, or operations.

### **Standards Development Process**

Unknown

### **Type of Content**

Broad range of social services content

### **Unit of Collection**

Individual

### **Data Availability**

Through various reporting programs





### **Relationship to other Standards**

By law, a SACWIS is required to support the reporting of data to the Adoption and Foster Care Analysis Reporting System (AFCARS) and the National Child Abuse and Neglect Data System (NCANDS). Furthermore, a SACWIS is expected to have bi-directional interfaces with a state's Title IV-A (Temporary Assistance for Needy Families), Title XIX (Medicaid), and Title IV-D (Child Support) systems. States are encouraged to add complementary functionality to their SACWIS, such as functionality that supports child protective services, thereby providing a unified automated tool to support all child welfare services. States may incorporate other programs into a SACWIS (such as TANF emergency assistance, juvenile justice, mental health, and adult protective services) or provide access for other human service professionals (such as family courts, schools, medical providers, and providers of services to stabilize families and ensure child well-being).

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Yes

### **Key Documents and Reports**

Status of each state's SACWIS project: <http://www.acf.hhs.gov/programs/cb/systems/sacwis/statestatus.htm>

SACWIS-related guidance documents: <http://www.acf.hhs.gov/programs/cb/systems/sacwis/federal.htm>

### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families:  
<http://www.acf.hhs.gov/programs/cb/systems/index.htm>

### **For More Information**

Christine M. Calpin  
Associate Commissioner  
Children's Bureau  
370 L'Enfant Promenade SW  
Washington, DC 20024

### **Reviewed**

No



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# COMMUNITY RESOURCES





## Alliance of Information and Referral Systems Standard (AIRS XSD)

### **Sector**

Community Resources

### **Type of Standard**

Data Interoperability Standard

### **Sponsor**

Alliance of Information and Referral Systems (AIRS)

### **Purpose**

AIRS XSD supports community resource database interoperability. Community resource databases may include those maintained by 2-1-1 Call Centers, Area Agencies on Aging, searchable resources Web sites, libraries, and other organizations that seek to compile information about health and human services.

### **Version**

AIRS XSD 3.0

### **Year Current Version Was Adopted**

2008

### **Age of Standard**

2004

### **Federal Involvement/Endorsement**

None

### **Who Uses**

Information and referral organizations, such as 2-1-1 call centers so that data about community resources may be shared

### **Mandatory/Voluntary (and Authorization)**

Voluntary

### **Estimate of Adoption**

Unknown





## **Standards Development Process**

The AIRS Board approves all major standards versioning. A subcommittee of the Technology Committee, the AIRS XSD Workgroup, is responsible for making recommendations to the Board. A separate advisory group, representing vendors, advises the AIRS XSD Workgroup.

## **Type of Content**

Human services agencies and programs, including types of services, contact information, hours of service, eligibility criteria, type of organization, fees, and so on

## **Unit of Collection**

Program service and agency level

## **Data Availability**

The standard is for exchange between organizations. No data is collected.

## **Relationship to other Standards**

AIRS XSD refers to the LA211/AIRS Taxonomy for Health and Human Services to code the type of services that organizations provide.

## **Future Plans**

The AIRS XSD plans to develop a content-specific XSD that will flexibly define undefined fields and also to create import specifications.

## **Vendors Incorporating In Products**

Yes. A number of the major vendors in the information and referral field have participated in the development of the AIRS XSD and have also developed utilities to create compliant exports.

## **Key Documents and Reports**

AIRS XSD 3.0: [http://www.airs.org/files/public/AIRS\\_XSD\\_3\\_0.doc](http://www.airs.org/files/public/AIRS_XSD_3_0.doc)

AIRS Style Guide: [http://www.airs.org/files/public/AIRS\\_StyleGuide\\_FinalMarch2007.doc](http://www.airs.org/files/public/AIRS_StyleGuide_FinalMarch2007.doc)

AIRS XSD Web site: <http://www.airs.org/i4a/pages/index.cfm?pageid=3363>

## **Web Site**

AIRS Web site: <http://www.airs.org/i4a/pages/index.cfm?pageid=1>





### **For More Information**

Marianne Galleon, Technology Director 211 LA County and  
Technology Chair, Alliance of Information and Referral Systems  
Los Angeles, CA  
Telephone: (626) 350-1841, ext. 2122  
E-mail: [marianne@211la.org](mailto:marianne@211la.org)

Reviewed

No





# National Information Exchange Model (NIEM)

## Sector

Community Resources  
Corrections  
Criminal Justice/Courts  
Emergency/Disaster

## Type of Standard

Overarching Framework  
Data Interoperability Standards

## Sponsor

National Information Exchange Model (NIEM) is a joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice with outreach to other departments and agencies.

## Purpose

NIEM is designed to develop, disseminate, and support enterprisewide information exchange standards and processes that can enable jurisdictions to effectively share critical information in emergency situations, as well as support the day-to-day operations of agencies throughout the nation.

## Version

NIEM 2.0

## Year Current Version Was Adopted

2007

## Age of Standard

2005

## Federal Involvement/Endorsement

Joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice, as well as supported by the Global Justice Information Sharing Initiative. There have also been discussions with other interest groups that are expected to result in broader involvement. For example, the U.S. Department of the Navy has begun to partner with NIEM to address maritime domain information sharing requirements.

## Who Uses

All levels of government and industry to ensure homeland security and public safety, including: law



enforcement; courts; prosecution; corrections; emergency management; fire and EMS; immigration; customs; international trade; transportation security; intelligence; and family services (juvenile justice, child welfare, and child support)

### **Mandatory/Voluntary (and Authorization)**

NIEM is recognized as a voluntary standard, built by a national consensus process by which the user communities are directly involved in the development of the data model. Therefore, DOJ and DHS support NIEM adoption by providing special conditions in certain grants that require the use of NIEM when applicable, thus promoting larger scale adoption and use of the practitioner-driven model.

NIEM is supportive of the Homeland Security Presidential Directive (HSPD-5), which assigns the Secretary of the Department of Homeland Security the role of principal federal official for domestic incident management. The Homeland Security Act of 2002 charges the Secretary with the responsibility for coordinating federal operations within the United States to prepare for, respond to, and recover from terrorist attacks, major disasters, and other emergencies. Building on this foundation is a series of Executive Orders which direct agencies to improve the exchange of terrorism information and protect their ability to acquire information.

### **Estimate of Adoption**

NIEM adoption has been required at the federal level through the CIO organizations of DOJ (through One-DOJ and LEISP) and DHS (through the Enterprise Data Management Office). Numerous projects within both Departments are currently based on NIEM as a data exchange platform. NIEM is being adopted statewide in several instances including New York, Florida, Minnesota, and Texas; and dozens of local and regional projects, in at least 36 states, have been identified as well.

### **Standards Development Process**

NIEM is a multiagency information sharing program. Intergovernmental groups representing key stakeholders play an important role in creating and sustaining partnerships. Partners can share knowledge and resources across the government and ensure that NIEM provides true value to citizens. Because of the inherent complexity of issues and jurisdictional control, an organizational structure is a necessary first step to ensure that the stakeholders are intimately involved in the project. These NIEM governance bodies include the Executive Steering Committee, Policy Advisory Panel, NIEM Program Management Office, and several working-level committees focused on technical and business requirements, and communications and outreach. The NIEM Executive Steering Committee represents key public decision makers from DOJ, DHS, and the Global Justice Information Sharing Initiative, as well as their constituents, who have a significant vested interest in NIEM objectives. The Executive Steering Committee provides strategic direction to the Program Management Office, whose responsibilities are to oversee the implementation and development of NIEM.





## **Type of Content**

Data exchange standards for information that is commonly shared across the broad justice, public safety, emergency and disaster management, intelligence, and homeland security enterprises

NIEM in whole consists of several key parts. The most often referenced is the data model, comprised of over 7,000 standard element names, presented as xml tags. The second is a data dictionary, providing a standard, operational definition for each of those elements. Third, NIEM presents a broad suite of tools to assist in discovery and use of the model. Finally, NIEM also includes a standardized methodology for implementing NIEM, the Information Exchange Package Documentation (IEPD) specification. This IEPD specification prescribes a life cycle methodology for the development of information exchanges, which is grounded in subject matter expertise; it also prescribes a standard means of constructing the xml schema by defining the finite subset of NIEM data elements that will be used for a particular exchange. These tools and specifications help to ensure rapid adoption and facilitate reuse of existing work (saving time, energy, and money otherwise spent “reinventing the wheel” across implementations).

## **Unit of Collection**

The current domains in NIEM include justice, intelligence, immigration, emergency management, international trade, and infrastructure protection. NIEM includes xml tags that serve as standard element names as well as standard definitions for over 7,000 individual data elements. NIEM does not itself collect data—it is better conceived as a standard that includes standardized metadata.

## **Data Availability**

NIEM as a program does not own any data; it simply defines the format and structure of a data exchange model.

## **Relationship to other Standards**

NIEM leverages the data exchange standards efforts successfully implemented by the Global Justice Information Sharing Initiative and extends the Global Justice XML Data Model (GJXDM) to facilitate timely and secure information sharing across the whole of the justice, public safety, emergency and disaster management, intelligence, and homeland security domains. It also references existing standards, including the ANSI-NIST standard for fingerprint and other biometric data, as well as the Emergency Data Management (EDXL) messaging standard for emergency response.

In addition, the justice community has developed messaging standards to ease architectural specification and implementation. The Logical Entity eXchange Specification (LEXS) builds on top of NIEM and assists in message routing and data rendering, and the Justice Reference Architecture (JRA) provides a Service-Oriented Architecture framework that leverages NIEM as the data payload.



## Future Plans

NIEM efforts will concentrate on:

- **Core Capability Development and Maintenance:** This effort focuses on delivering NIEM 2.0 and subsequent releases; fully implementing NIEM governance; representing the critical mass of justice, homeland security, and intelligence information exchanges in their associated domains; developing a tools road map based on user requirements and delivering the tools into operation; and launching outreach activities (including the Web site), conference presentations, and training.
- **Information Exchange Standard Development:** This effort focuses on developing families of Information Exchange Package Documentation (IEPD) representing core, priority business areas at the national level. The initial focus areas will include incident reporting, people screening, suspicious activities, cargo screening, emergency and disaster management, and case management. Policies and processes will be developed to support creating, modifying, and implementing these standards. Nothing in this statement precludes communities of interest (COIs) from championing and developing information exchange standards within their domains or for multiple COIs to do so cooperatively, with direct sponsorship from the NIEM PMO. They will follow the NIEM IEPD development process.
- **Outreach and Implementation:** This effort focuses on identifying additional pilots at the local, state, and tribal levels, targeting the emerging information exchange standards mentioned above and implementing the infrastructure needed for training and technical assistance, including a help desk.
- **Additional domains being addressed for the next release** include Maritime Domain Awareness, Child and Family Services, and others.

## Vendors Incorporating In Products

Like federal, state, local and tribal adoption and use, the incorporation of NIEM into private-sector, third-party products is difficult to estimate. The effort is supported by the Integrated Justice Information Systems Institute (IJIS): “a nonprofit membership organization ... [composed primarily] of information technology companies and consultancies that provide products or services to the justice, public safety, and homeland security sectors for the purpose of helping these communities share information.” ([www.ijis.org](http://www.ijis.org))

## Key Documents and Reports

Executive Message: [http://www.niem.gov/files/NIEM\\_Executive\\_Briefing.pdf](http://www.niem.gov/files/NIEM_Executive_Briefing.pdf)

NIEM Introduction Manual: [http://www.niem.gov/files/NIEM\\_Introduction.pdf](http://www.niem.gov/files/NIEM_Introduction.pdf)

NIEM User Guide: [http://www.niem.gov/pdf/NIEM\\_User\\_Guide.pdf](http://www.niem.gov/pdf/NIEM_User_Guide.pdf)

The NIEM specification and a variety of documents and downloads: <http://www.niem.gov/library.php>





### **Web Site**

NIEM Web site: <http://www.niem.gov/>

### **For More Information**

Christopher Traver

Senior Policy Advisor

Bureau of Justice Assistance

U.S. Department of Justice

810 Seventh Street NW

Washington, DC 20531

Telephone: (202) 307-2963

Facsimile: (202) 307-0036

E-mail: [christopher.traver@usdoj.gov](mailto:christopher.traver@usdoj.gov)

### **Reviewed**

Yes





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# CORRECTIONS





# Corrections Technology Association Corrections Data Exchange Standards Project

**Sector**

Corrections

**Type of Standard**

Data Interoperability Standard

**Sponsor**

Corrections Technology Association

**Purpose**

In support of public safety, correctional agency administrators need to exchange information timely and accurately with criminal justice entities and non-criminal justice entities (for example, departments of Motor Vehicles, Health Agencies, Social Services, Immigration and Naturalization, Social Security Administration, and so forth) at the local, state, and federal levels.

**Version**

In proposal stage only

**Year Current Version Was Adopted**

In proposal stage only

**Age of Standard**

In proposal stage only

**Federal Involvement/Endorsement**

Unknown

**Who Uses**

In proposal stage only

**Mandatory/Voluntary (and Authorization)**

In proposal stage only

**Estimate of Adoption**

In proposal stage only





## **Standards Development Process**

In proposal stage only

## **Type of Content**

In proposal stage only

## **Unit of Collection**

In proposal stage only

## **Data Availability**

In proposal stage only

## **Relationship to other Standards**

This standard is built upon the National Information Exchange Model (NIEM) framework.

## **Future Plans**

In proposal stage only

## **Vendors Incorporating In Products**

In proposal stage only

## **Key Documents and Reports**

CTA Standards Committee Corrections Data Exchange Standards Project Draft

Project Charter (last updated 2002): <http://www.correctionstech.org/StandardsCommittee/DataExchangeStandardsProject.doc>

## **Web Site**

Corrections Technology Association: <http://www.correctionstech.org/committeesStandards.php>

## **For More Information**

Unknown, but contact could be tracked through NIEM

## **Reviewed**

No





## National Information Exchange Model (NIEM)

### Sector

Community Resources  
Corrections  
Criminal Justice/Courts  
Emergency/Disaster

### Type of Standard

Overarching Framework  
Data Interoperability Standards

### Sponsor

National Information Exchange Model (NIEM) is a joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice with outreach to other departments and agencies.

### Purpose

NIEM is designed to develop, disseminate and support enterprisewide information exchange standards and processes that can enable jurisdictions to effectively share critical information in emergency situations, as well as support the day-to-day operations of agencies throughout the nation.

### Version

NIEM 2.0

### Year Current Version Was Adopted

2007

### Age of Standard

2005

### Federal Involvement/Endorsement

Joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice, as well as supported by the Global Justice Information Sharing Initiative. There have also been discussions with other interest groups that are expected to result in broader involvement. For example, the U.S. Department of the Navy has begun to partner with NIEM to address maritime domain information sharing requirements.



## **Who Uses**

All levels of government and industry to ensure homeland security and public safety, including: law enforcement; courts; prosecution; corrections; emergency management; fire and EMS; immigration; customs; international trade; transportation security; intelligence; and family services (juvenile justice, child welfare, and child support)

## **Mandatory/Voluntary (and Authorization)**

NIEM is recognized as a voluntary standard, built by a national consensus process by which the user communities are directly involved in the development of the data model. Therefore, DOJ and DHS support NIEM adoption by providing special conditions in certain grants that require the use of NIEM when applicable, thus promoting larger scale adoption and use of the practitioner-driven model.

NIEM is supportive of the Homeland Security Presidential Directive (HSPD-5), which assigns the Secretary of the Department of Homeland Security the role of principal federal official for domestic incident management. The Homeland Security Act of 2002 charges the Secretary with the responsibility for coordinating federal operations within the United States to prepare for, respond to, and recover from terrorist attacks, major disasters, and other emergencies. Building on this foundation is a series of Executive Orders which direct agencies to improve the exchange of terrorism information and protect their ability to acquire information.

## **Estimate of Adoption**

NIEM adoption has been required at the federal level through the CIO organizations of DOJ (through One-DOJ and LEISP) and DHS (through the Enterprise Data Management Office). Numerous projects within both Departments are currently based on NIEM as a data exchange platform. NIEM is being adopted statewide in several instances, including New York, Florida, Minnesota, and Texas, and dozens of local and regional projects, in at least 36 states, have been identified as well.

## **Standards Development Process**

NIEM is a multiagency information sharing program. Intergovernmental groups representing key stakeholders play an important role in creating and sustaining partnerships. Partners can share knowledge and resources across the government and ensure that NIEM provides true value to citizens. Because of the inherent complexity of issues and jurisdictional control, an organizational structure is a necessary first step to ensure that the stakeholders are intimately involved in the project. These NIEM governance bodies include the Executive Steering Committee, Policy Advisory Panel, NIEM Program Management Office, and several working level committees focused on technical and business requirements and communications and outreach. The NIEM Executive Steering Committee represents key public decisionmakers from DOJ, DHS, and the Global Justice Information Sharing Initiative, as well as their constituents, who have a significant vested interest in NIEM objectives. The Executive Steering Committee provides strategic direction to the Program Management Office,





whose responsibilities are to oversee the implementation and development of NIEM.

### **Type of Content**

Data exchange standards for information that is commonly shared across the broad justice, public safety, emergency and disaster management, intelligence, and homeland security enterprises

NIEM, in whole, consists of several key parts. The most often referenced is the data model, comprised of over 7,000 standard element names, presented as xml tags. The second is a data dictionary, providing a standard, operational definition for each of those elements. Third, NIEM presents a broad suite of tools to assist in discovery and use of the model. Finally, NIEM also includes a standardized methodology for implementing NIEM, the Information Exchange Package Documentation (IEPD) specification. This IEPD specification prescribes a life cycle methodology for the development of information exchanges, which is grounded in subject matter expertise; it also prescribes a standard means of constructing the xml schema by defining the finite subset of NIEM data elements that will be used for a particular exchange. These tools and specifications help to ensure rapid adoption and facilitate reuse of existing work (saving time, energy, and money otherwise spent “reinventing the wheel” across implementations).

### **Unit of Collection**

The current domains in NIEM include justice, intelligence, immigration, emergency management, international trade, and infrastructure protection. NIEM includes xml tags that serve as standard element names as well as standard definitions for over 7,000 individual data elements. NIEM does not itself collect data—it is better conceived as a standard that includes standardized metadata.

### **Data Availability**

NIEM as a program does not own any data; it simply defines the format and structure of a data exchange model.

### **Relationship to other Standards**

NIEM leverages the data exchange standards efforts successfully implemented by the Global Justice Information Sharing Initiative and extends the Global Justice XML Data Model (GJXDM) to facilitate timely and secure information sharing across the whole of the justice, public safety, emergency and disaster management, intelligence, and homeland security domains. It also references existing standards, including the ANSI-NIST standard for fingerprint and other biometric data, as well as the Emergency Data Management (EDXL) messaging standard for emergency response.

In addition, the justice community has developed messaging standards to ease architectural specification and implementation. The Logical Entity eXchange Specification (LEXS) builds on top of NIEM and assists in message routing and data rendering, and the Justice Reference Architecture (JRA) provides a Service-Oriented Architecture framework that leverages NIEM as the data payload.





## Future Plans

NIEM efforts will concentrate on:

- **Core Capability Development and Maintenance:** This effort focuses on delivering NIEM 2.0 and subsequent releases; fully implementing NIEM governance; representing the critical mass of justice, homeland security, and intelligence information exchanges in their associated domains; developing a tools roadmap based on user requirements and delivering the tools into operation; and launching outreach activities (including the Web site), conference presentations, and training.
- **Information Exchange Standard Development:** This effort focuses on developing families of Information Exchange Package Documentation (IEPD) representing core, priority business areas at the national level. The initial focus areas will include incident reporting, people screening, suspicious activities, cargo screening, emergency and disaster management, and case management. Policies and processes will be developed to support creating, modifying, and implementing these standards. Nothing in this statement precludes communities of interest (COIs) from championing and developing information exchange standards within their domains or for multiple COIs to do so cooperatively, with direct sponsorship from the NIEM PMO. They will follow the NIEM IEPD development process.
- **Outreach and Implementation:** This effort focuses on identifying additional pilots at the local, state, and tribal levels, targeting the emerging information exchange standards mentioned above and implementing the infrastructure needed for training and technical assistance, including a help desk.
- **Additional domains being addressed for the next release** include Maritime Domain Awareness, Child and Family Services, and others.

## Vendors Incorporating In Products

Like federal, state, local, and tribal adoption and use, the incorporation of NIEM into private-sector, third-party products is difficult to estimate. The effort is supported by the Integrated Justice Information Systems Institute (IJIS): “a nonprofit membership organization ...[composed primarily] of information technology companies and consultancies that provide products or services to the justice, public safety, and homeland security sectors for the purpose of helping these communities share information.” ([www.ijis.org](http://www.ijis.org))

## Key Documents and Reports

Executive Message: [http://www.niem.gov/files/NIEM\\_Executive\\_Briefing.pdf](http://www.niem.gov/files/NIEM_Executive_Briefing.pdf)

NIEM Introduction Manual: [http://www.niem.gov/files/NIEM\\_Introduction.pdf](http://www.niem.gov/files/NIEM_Introduction.pdf)

NIEM User Guide: [http://www.niem.gov/pdf/NIEM\\_User\\_Guide.pdf](http://www.niem.gov/pdf/NIEM_User_Guide.pdf)





The NIEM specification and a variety of documents and downloads: <http://www.niem.gov/library.php>

### **Web Site**

NIEM Web site: <http://www.niem.gov/>

### **For More Information**

Christopher Traver  
Senior Policy Advisor  
Bureau of Justice Assistance  
U.S. Department of Justice  
810 Seventh Street NW  
Washington, DC 20531  
Telephone: (202) 307-2963  
Facsimile: (202) 307-0036  
E-mail: [christopher.traver@usdoj.gov](mailto:christopher.traver@usdoj.gov)

### **Reviewed**

Yes



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# CRIMINAL JUSTICE/COURTS





# Child Support and Court/Judicial Message Exchange Data Model

## **Sector**

Child and Family Services  
Criminal Justice/Courts

## **Type of Standard**

Data Interoperability Standard

## **Sponsor**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement and Conference of Chief Justices within the National Center for State Courts

## **Purpose**

Child Support and Court/Judicial Message Exchange Data Model provides data standards for the Child Support community to facilitate an automated data exchange with the courts/judiciary.

## **Version**

2008

## **Year Current Version Was Adopted**

2008

## **Age of Standard**

Endorsed by the Federal Office of Child Support Enforcement Oversight Board and by the Conference of Chief Justices within the National Center for State Courts in 2008

## **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement

## **Who Uses**

State Child Support Enforcement agencies and courts

## **Mandatory/Voluntary (and Authorization)**

While this exchange is not mandated, adoption is highly recommended since it meets the business needs to provide a common structure for automated exchange of information and documents between participating child support enforcement agencies and courts.



### **Estimate of Adoption**

A proof of concept using these standards is under development by Colorado, which will provide the courts and CSE communities with valuable insight to the implementation of the data exchanges.

### **Standards Development Process**

The Federal Office of Child Support Enforcement Data Standards Oversight Board endorsed the Child Support and Court/Judicial Message Exchange Data Model, and vetting through the National Center for State Courts Joint Technology Committee

### **Type of Content**

Case data, obligor/person data, obligee/person data, child data, financial and event data.

### **Unit of Collection**

Family

### **Data Availability**

A proof of concept using these standards is under development by Colorado, which will provide the courts and CSE communities with valuable insight to the implementation of the data exchanges.

### **Relationship to other Standards**

The new data standards were developed through integration of the National Information Exchange Model (NIEM) and CSE standards. NIEM is a culmination of the Global Justice XML Data Model (GJXDM) and Legal XML, pioneer efforts in exchange model.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

National Judicial-Child Support Task Force business case templates to support the states and courts in their electronic exchange of information: <http://www.acf.hhs.gov/programs/cse/pol/DCL/2008/dcl-08-01.htm>

### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Child Support Enforcement: <http://www.acf.hhs.gov/programs/cse>





Joint Technology Committee of the National Center for State Courts:

[http://www.ncsconline.org/d\\_tech/gjxdm/IEPD.asp#ChildSupport](http://www.ncsconline.org/d_tech/gjxdm/IEPD.asp#ChildSupport)

**For More Information**

Richard Ordowich

Coordinator for Data Quality/Data Standards, Office of Child Support Enforcement

U.S. Department of Health and Human Services

Telephone: (202) 260-5495

E-mail: [richard.ordowich@acf.hhs.gov](mailto:richard.ordowich@acf.hhs.gov)

**Reviewed**

No







## Justice Reference Architecture (JRA)

### Sector

Criminal Justice/Courts

### Type of Standard

Overarching Framework

### Sponsor

U.S. Department of Justice, Office of Justice Programs, Global Justice Information Sharing Initiative

### Purpose

The Global JRA Specification is intended to be a technical implementation architecture that addresses the full range of information sharing use cases and provides a comprehensive blueprint for implementing interoperable data sharing services and capabilities. The initiative is based on the belief that this dynamic interoperability strategy will help to prevent incompatibilities, guide vendors and organizations on how to fit components together, and facilitate communication and interoperability between disparate communities. The JRA Specification is a conceptual framework for SOA that is based on an industry standard, the OASIS SOA Reference Model, which was developed by a committee of industry and government SOA experts, including some of the GISWG members who authored the JRA. The Specification defines a set of key concepts in a standard way, so that across the country, justice practitioners and their industry partners can adopt a consistent vocabulary for communicating about SOA. The framework also provides a jumping-off point for the rest of the broader reference architecture by identifying areas where the community needs more thorough standards and guidelines.

### Version

1.7

### Year Current Version was Adopted

2008

### Age of Standard

2007

### Federal Involvement/Endorsement

U.S. Department of Justice, Office of Justice Programs, Global Justice Information Sharing Initiative



## **Who Uses**

The target audience for the reference architecture and guidance is any group or set of justice partners that want to share information and agree to implement common business rules and infrastructure requirements. Global JRA Specifications Version 1.7 includes a set of requirements for justice interoperability, describes the Justice Reference Architecture (concepts, relationships, and high-level components), and provides specifications that satisfy those requirements. As the GISWG work evolves, other planned documents include a Concept of Operations, Service Modeling Guidelines, and Service Interaction Profiles.

## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

Unknown

## **Type of Content**

Four core concepts make up the core of the JRA:

1. The JRA begins from the premise that a group of justice partners have business CAPABILITIES that they provide to one another.
2. The JRA calls these systems provider systems. Each capability produces one or more REAL-WORLD EFFECTS, each of which is an outcome of the business value sought by one of the partners.
3. In a service-oriented architecture, a SERVICE is the way in which one partner gains access to a capability offered by another partner.
4. A partner that uses a service to gain access to another partner's capability is called a SERVICE CONSUMER. As with capabilities, the architecture is generic enough to support virtually any kind of service consumer. However, since the purpose of the JRA is to describe an approach to information systems interoperability, the JRA narrows the SOA-RM definition of service consumer to information systems that interact with services directly through an interface that conforms to a service interaction profile.





The remainder of the concepts in the JRA deal with the following three important concerns:

- How consumers may find out that a service exists
- Once they find the service, how consumers may understand what the service does and what information flows in and out of it
- How a consumer may reach and interact or communicate with the service

### **Unit of Collection**

See above

### **Data Availability**

Unknown

### **Relationship to other Standards**

Relates to Global Justice XML Data Model (Global JXDM) and National Information Exchange Model (NIEM). Global adopted the Organization for the Advancement of Structured Information Standards (OASIS) Reference Model for Service-Oriented Architecture 1.0 [SOA-RM]. OASIS has approved this standard reference model for describing different architectures using comparable, vendor-neutral language. Global is adopting the OASIS framework for describing its architecture and holding conversations with other domains.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

U.S. Department of Justice's Global Justice Reference Architecture (JRA) Specification (version 1.7):  
[http://www.it.ojp.gov/documents/JRA\\_Specification\\_1-7.doc](http://www.it.ojp.gov/documents/JRA_Specification_1-7.doc)

### **Web Site**

U.S. Department of Justice, Office of Justice Programs, Global Justice Information Sharing Initiative:  
<http://www.it.ojp.gov/default.aspx?area=nationalInitiatives&page=1015>



**For More Information**

Christopher Traver

Senior Policy Advisor

Bureau of Justice Assistance

U.S. Department of Justice

Telephone: (202) 307-2963

E-mail: [christopher.traver@usdoj.gov](mailto:christopher.traver@usdoj.gov)

**Reviewed**

No





# Law Enforcement Information Sharing Program (LEISP) Exchange Specifications (LEXS)

## Sector

Criminal Justice/Courts

## Type of Standard

Data Interoperability Standard

## Sponsor

U.S. Department of Justice, Federal Bureau of Investigation, Criminal Justice Information Services Division

## Purpose

The LEISP Exchange Specification (LEXS) defines a common format in which law enforcement data can be shared. The most commonly used elements form the foundation upon which practitioners can build specialized extensions to suit individual communities.

## Version

LEXS 3.1

## Year Current Version Was Adopted

2008

## Age of Standard

2005

## Federal Involvement/Endorsement

U.S. Department of Justice, Office of Justice Programs

## Who Uses

Local, state, tribal, and federal law enforcement and homeland security systems

## Mandatory/Voluntary (and Authorization)

Voluntary

## Estimate of Adoption

Unknown



## **Standards Development Process**

A collaborative process involving senior leadership from DOJ component agencies and representatives from across the national law enforcement community

## **Type of Content**

Person and roles, organizational associations, locational information, controlled substances, transportation, activities, and contact information

## **Unit of Collection**

Individual

## **Data Availability**

## **Relationship to other Standards**

LEXS is a flexible, NIEM-based framework used for the creation of NIEM-conformant Information Exchange Package Documentations for information sharing, both for publishing information and for system-to-system federated searches.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Yes

## **Key Documents and Reports**

LEXS 3.1 User Guide and Other Documentation: <http://www.it.ojp.gov/default.aspx?area=implementationAssistance&page=1017&standard=486>

## **Web Site**

U.S. Department of Justice, Office of Justice Programs, Justice Standards Clearinghouse: <http://www.it.ojp.gov/default.aspx?area=implementationAssistance&page=1017&standard=486>





**For More Information**

Sudhi Umarji

U.S. Department of Justice

950 Pennsylvania Avenue

Washington, DC 20530

Telephone: (301) 354-6062

E-mail: [sudhi.umarji@usdoj.gov](mailto:sudhi.umarji@usdoj.gov)

**Reviewed**

No







# Law Enforcement National Data Exchange (N-DEx)

**Sector**

Criminal Justice/Courts

**Type of Standard**

Data Interoperability Standard

**Sponsor**

U.S. Department of Justice, Federal Bureau of Investigation, Criminal Justice Information Services Division

**Purpose**

N-DEx is a criminal justice information sharing system that will provide nationwide connectivity to disparate local, state, tribal, and federal systems for the exchange of information. N-DEx will provide law enforcement agencies with a powerful new investigative tool to search, link, analyze, and share information (for example, incident and case reports) on a national basis to a degree never before possible. N-DEx will primarily benefit local law enforcement in their role as the first line of defense against crime and terrorism.

**Version**

2008 - Operational March 19, 2008, Increment 1 - Initial Deployment: sharing of incident/case report information, correlation (basic), visualization (basic), search, analytical reporting, federated search, initial support 50,000

**Year Current Version Was Adopted**

2008

**Age of Standard**

2008

**Federal Involvement/Endorsement**

U.S. Department of Justice, Federal Bureau of Investigation, Criminal Justice Information Services Division

**Who Uses**

Local, state, tribal, and federal law enforcement systems

**Mandatory/Voluntary (and Authorization)**

Voluntary



## **Estimate of Adoption**

Although a new standard, law enforcement agencies appear to be adopting. As of February 2009, there were just under 17 law enforcement systems (some statewide) reporting data and 54 million records in N-DEx.

## **Standards Development Process**

N-DEx governance and policies are managed and developed cooperatively with the law enforcement community; they are not mandated by the federal government.

## **Type of Content**

Currently, law enforcement agencies have the ability to share incident/case report data and arrest data and to open and closed investigative case data. In the summer of 2009, N-DEx will expand capabilities to allow these agencies to share booking and incarceration data. In the summer of 2010, N-DEx will expand capabilities to allow agencies to share probation and parole data.

## **Unit of Collection**

Incident, Event, Case, Incarceration, Booking, Arrest, Probation, and Parole

## **Data Availability**

Law enforcement agencies must:

- Sign an operational Memorandum of Understanding (MOU)
- Identify and map incident/case data to the N-DEx Information
- Information Exchange Package Documentation (IEPD)
- Obtain network connectivity through an existing CJIS Wide-Area Network (WAN) or connect over the Law Enforcement Online (LEO)

## **Relationship to other Standards**

Agencies must adhere to national standards for efficient sharing of data.

- National Information Exchange Model (NIEM)
- Law Enforcement Information Sharing Program (LEISP) Exchange Specification (LEXS)

## **Future Plans**

Summer 2009, Increment 2 – Second Deployment: add data sets (arrest, booking, and incarceration data), correlation (advanced), visualization (advanced), subscription/notification, 100,000 users, collaboration, auto processing, increment 1 operation and maintenance





Summer 2010, Increment 3 – Full Operational Capacity: add data sets (probation/parole data), enhancements and modifications previously deployed, analytical reporting (advanced), rolled out nationally to participants, 200,000 users, increment 2 operations and maintenance

### **Vendors Incorporating In Products**

Yes

### **Key Documents and Reports**

Information about N-DEX may be found at the U.S. Department of Justice Standards Clearinghouse:

<http://www.it.ojp.gov/default.aspx?area=implementationAssistance&page=1017>

### **Web Site**

FBI Web site: [http://www.fbi.gov/hq/cjisd/ndex/ndex\\_home.htm](http://www.fbi.gov/hq/cjisd/ndex/ndex_home.htm)

### **For More Information**

Ed Waigand

Law Enforcement National Data Exchange

Criminal Justice Information Services

Federal Bureau of Investigation

1000 Custer Hollow Road

Clarksburg, WV 26306

Telephone: (304) 625-4232

Facsimile: (304) 625-3456

E-mail: [ewaigand@leo.gov](mailto:ewaigand@leo.gov)

### **Reviewed**

Yes





## National Information Exchange Model (NIEM)

### Sector

Community Resources  
Corrections  
Criminal Justice/Courts  
Emergency/Disaster

### Type of Standard

Overarching Framework  
Data Interoperability Standards

### Sponsor

National Information Exchange Model (NIEM) is a joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice with outreach to other departments and agencies.

### Purpose

NIEM is designed to develop, disseminate and support enterprisewide information exchange standards and processes that can enable jurisdictions to effectively share critical information in emergency situations, as well as support the day-to-day operations of agencies throughout the nation.

### Version

NIEM 2.0

### Year Current Version Was Adopted

2007

### Age of Standard

2005

### Federal Involvement/Endorsement

Joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice, as well as supported by the Global Justice Information Sharing Initiative. There have also been discussions with other interest groups that are expected to result in broader involvement. For example, the U.S. Department of the Navy has begun to partner with NIEM to address maritime domain information sharing requirements.

### Who Uses

All levels of government and industry to ensure homeland security and public safety, including: law



enforcement; courts; prosecution; corrections; emergency management; fire and EMS; immigration; customs; international trade; transportation security; intelligence; and family services (juvenile justice, child welfare, and child support)

### **Mandatory/Voluntary (and Authorization)**

NIEM is recognized as a voluntary standard, built by a national consensus process by which the user communities are directly involved in the development of the data model. Therefore, DOJ and DHS support NIEM adoption by providing special conditions in certain grants that require the use of NIEM when applicable, thus promoting larger scale adoption and use of the practitioner-driven model.

NIEM is supportive of the Homeland Security Presidential Directive (HSPD-5), which assigns the Secretary of the Department of Homeland Security the role of principal federal official for domestic incident management. The Homeland Security Act of 2002 charges the Secretary with the responsibility for coordinating federal operations within the United States to prepare for, respond to, and recover from terrorist attacks, major disasters, and other emergencies. Building on this foundation is a series of Executive Orders which direct agencies to improve the exchange of terrorism information and protect their ability to acquire information.

### **Estimate of Adoption**

NIEM adoption has been required at the federal level through the CIO organizations of DOJ (through One-DOJ and LEISP) and DHS (through the Enterprise Data Management Office). Numerous projects within both Departments are currently based on NIEM as a data exchange platform. NIEM is being adopted statewide in several instances, including New York, Florida, Minnesota, and Texas; and dozens of local and regional projects, in at least 36 states, have been identified as well.

### **Standards Development Process**

NIEM is a multiagency information sharing program. Intergovernmental groups representing key stakeholders play an important role in creating and sustaining partnerships. Partners can share knowledge and resources across the government and ensure that NIEM provides true value to citizens. Because of the inherent complexity of issues and jurisdictional control, an organizational structure is a necessary first step to ensure that the stakeholders are intimately involved in the project. These NIEM governance bodies include the Executive Steering Committee, Policy Advisory Panel, NIEM Program Management Office, and several working-level committees focused on technical and business requirements and communications and outreach. The NIEM Executive Steering Committee represents key public decision makers from DOJ, DHS, and the Global Justice Information Sharing Initiative, as well as their constituents, who have a significant vested interest in NIEM objectives. The Executive Steering Committee provides strategic direction to the Program Management Office, whose responsibilities are to oversee the implementation and development of NIEM.





## **Type of Content**

Data exchange standards for information that is commonly shared across the broad justice, public safety, emergency and disaster management, intelligence, and homeland security enterprises

NIEM in whole consists of several key parts. The most often-referenced is the data model, comprised of over 7,000 standard element names, presented as xml tags. The second is a data dictionary, providing a standard, operational definition for each of those elements. Third, NIEM presents a broad suite of tools to assist in discovery and use of the model. Finally, NIEM also includes a standardized methodology for implementing NIEM, the Information Exchange Package Documentation (IEPD) specification. This IEPD specification prescribes a life cycle methodology for the development of information exchanges, which is grounded in subject matter expertise; it also prescribes a standard means of constructing the xml schema by defining the finite subset of NIEM data elements that will be used for a particular exchange. These tools and specifications help to ensure rapid adoption and facilitate reuse of existing work (saving time, energy and money otherwise spent “reinventing the wheel” across implementations).

## **Unit of Collection**

The current domains in NIEM include justice, intelligence, immigration, emergency management, international trade, and infrastructure protection. NIEM includes xml tags that serve as standard element names as well as standard definitions for over 7,000 individual data elements. NIEM does not itself collect data—it is better conceived as a standard that includes standardized metadata.

## **Data Availability**

NIEM as a program does not own any data; it simply defines the format and structure of a data exchange model.

## **Relationship to Other Standards**

NIEM leverages the data exchange standards efforts successfully implemented by the Global Justice Information Sharing Initiative and extends the Global Justice XML Data Model (GJXDM) to facilitate timely and secure information sharing across the whole of the justice, public safety, emergency and disaster management, intelligence, and homeland security domains. It also references existing standards, including the ANSI-NIST standard for fingerprint and other biometric data, as well as the Emergency Data Management (EDXL) messaging standard for emergency response.

In addition, the justice community has developed messaging standards to ease architectural specification and implementation. The Logical Entity eXchange Specification (LEXS) builds on top of NIEM and assists in message routing and data rendering, and the Justice Reference Architecture (JRA) provides a Service-Oriented Architecture framework that leverages NIEM as the data payload.





## Future Plans

NIEM efforts will concentrate on:

- **Core Capability Development and Maintenance:** This effort focuses on delivering NIEM 2.0 and subsequent releases; fully implementing NIEM governance; representing the critical mass of justice, homeland security, and intelligence information exchanges in their associated domains; developing a tools roadmap based on user requirements and delivering the tools into operation; and launching outreach activities (including the Web site), conference presentations, and training.
- **Information Exchange Standard Development:** This effort focuses on developing families of Information Exchange Package Documentation (IEPD) representing core, priority business areas at the national level. The initial focus areas will include incident reporting, people screening, suspicious activities, cargo screening, emergency and disaster management, and case management. Policies and processes will be developed to support creating, modifying, and implementing these standards. Nothing in this statement precludes communities of interest (COIs) from championing and developing information exchange standards within their domains or for multiple COIs to do so cooperatively, with direct sponsorship from the NIEM PMO. They will follow the NIEM IEPD development process.
- **Outreach and Implementation:** This effort focuses on identifying additional pilots at the local, state, and tribal levels, targeting the emerging information exchange standards mentioned above and implementing the infrastructure needed for training and technical assistance, including a help desk.
- **Additional domains being addressed for the next release** include Maritime Domain Awareness, Child and Family Services, and others.

## Vendors Incorporating In Products

Like federal, state, local, and tribal adoption and use, the incorporation of NIEM into private-sector, third-party products is difficult to estimate. The effort is supported by the Integrated Justice Information Systems Institute (IJIS): “a nonprofit membership organization ...[composed primarily] of information technology companies and consultancies that provide products or services to the justice, public safety, and homeland security sectors for the purpose of helping these communities share information.” ([www.ijis.org](http://www.ijis.org))

## Key Documents and Reports

Executive Message: [http://www.niem.gov/files/NIEM\\_Executive\\_Briefing.pdf](http://www.niem.gov/files/NIEM_Executive_Briefing.pdf)

NIEM Introduction Manual: [http://www.niem.gov/files/NIEM\\_Introduction.pdf](http://www.niem.gov/files/NIEM_Introduction.pdf)

NIEM User Guide: [http://www.niem.gov/pdf/NIEM\\_User\\_Guide.pdf](http://www.niem.gov/pdf/NIEM_User_Guide.pdf)

The NIEM specification and a variety of documents and downloads: <http://www.niem.gov/library.php>





### **Web Site**

NIEM Web site: <http://www.niem.gov>

### **For More Information**

Christopher Traver

Senior Policy Advisor

Bureau of Justice Assistance

U.S. Department of Justice

810 Seventh Street NW

Washington, DC 20531

Telephone: (202) 307-2963

Facsimile: (202) 307-0036

E-mail: [christopher.traver@usdoj.gov](mailto:christopher.traver@usdoj.gov)

### **Reviewed**

Yes





## **Uniform Crime Reports (UCR)/ National Incident-Based Reporting System (NIBRS)**

### **Sector**

Criminal Justice/Courts

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Justice, Federal Bureau of Investigation (FBI)

### **Purpose**

The UCR/NIBRS Program collects offense information for murder and non-negligent manslaughter, forcible rape, robbery, aggravated assault, burglary, larceny-theft, motor vehicle theft, and arson. It also collects information on the characteristics of persons arrested, victims and offenders in homicides and non-negligent manslaughter, and offenders in hate crimes.

### **Version**

2004

### **Year Current Version Was Adopted**

2004

### **Age of Standard**

1929 UCR

### **Federal Involvement/Endorsement**

U.S. Department of Justice, Federal Bureau of Investigation (FBI)

### **Who Uses**

City, university and college, county, state, tribal, and federal law enforcement agencies reporting data on crimes brought to their attention either through their respective state UCR Program or, for those states that do not have a state program, data is submitted directly to the FBI



## **Mandatory/Voluntary (and Authorization)**

### **Voluntary**

Section 515 of the Treasury and General Government Appropriations Act for Fiscal Year 2001 (Public Law 106-554) directs the Office of Management and Budget (OMB) to issue government-wide guidelines that “provide policy and procedural guidance to federal agencies for ensuring and maximizing the quality, objectivity, utility, and

integrity of information (including statistical information) disseminated by federal agencies.” The directive, which applies to the FBI in its administration of the UCR Program, stipulates that an agency that disseminates information to the public must provide “information quality guidelines that describe administrative mechanisms allowing affected persons to seek and obtain, where appropriate, correction of disseminated information that does not comply with the OMB and agency guidelines” (Federal Register, Vol. 67, No. 36).

### **Estimate of Adoption**

During 2004, law enforcement agencies active in the UCR/NIBRS Program represented 94.2 percent of the total number of law enforcement agencies.

### **Standards Development Process**

In 1988, a Data Providers’ Advisory Policy Board was established. That Board operated until 1993 when it combined with the National Crime Information Center Advisory Policy Board to form a single Advisory Policy Board (APB) to address all FBI criminal justice information services. The current APB advises the FBI concerning UCR policy and procedures. The UCR Subcommittee of the APB ensures continuing emphasis on UCR-related issues. The Association of State Uniform Crime Reporting Programs focuses on UCR issues within individual state law enforcement associations and also promotes interest in the UCR Program.

### **Type of Content**

Data on each incident and arrest within 22 offense categories made up of 46 specific crimes called Group A offenses. For each incident known to police within these categories, law enforcement collects administrative, offense, victim, property, offender, and arrestee information. In addition to the Group A offenses, there are 11 Group B offenses for which only arrest data are collected.

### **Unit of Collection**

The unit of analysis is arrests. One person may be arrested multiple times during the year; as a result, the arrest tabulations cannot be considered as a total number of individuals arrested.

### **Data Availability**

The FBI makes available, upon request, the files from the national database that was used to create Crime in the United States, Hate Crime Statistics, and Law Enforcement Officers Killed and Assaulted. These files may be





obtained by contacting the FBI's Communications Unit by telephone (304) 625-4995, facsimile (304) 625-5394, e-mail (cjis\_comm@leo.gov), or by writing to: Communications Unit, Criminal Justice Information Services Division, Federal Bureau of Investigation, Module D-3, 1000 Custer Hollow Road, Clarksburg, WV 26306-0154.

### **Relationship to other Standards**

Unknown

### **Future Plans**

The National Incident-Based Reporting System (NIBRS), which is compiled in addition to the UCR as summary reporting, covers 80 percent of the nation's reporting. The NIBRS collects data on each single incident and arrest within 22 crime categories. For each offense known to police within these categories, incident, victim, property, offender, and arrestee information are gathered when available. The goal of the redesign is to modernize crime information by collecting data currently maintained in law enforcement records while maintaining the integrity of UCR's long-running statistical series. Implementation of the NIBRS is occurring at a pace commensurate with the resources, abilities, and limitations of the contributing law enforcement agencies. In, 2004, 29 state programs had been certified for NIBRS participation. For current UCR reporting, NIBRS data are summarized in order to be combined with the UCR data. Contact information for the NIBRS is the same as for the UCR.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

The culmination of the national data collection effort is three annual publications: Crime in the United States, Hate Crime Statistics, and Law Enforcement Officers Killed and Assaulted.

UCR Handbook: <http://www.fbi.gov/ucr/handbook/ucrhandbook04.pdf>

### **Web Site**

The general Web site for the UCR is <http://www.fbi.gov/ucr/ucr.htm>

### **For More Information**

Unknown, but contact could be tracked through NIEM

### **Reviewed**

No



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# EMERGENCY/ DISASTER







## **ANSI-Homeland Security Standards Panel (ANSI-HSSP)**

### **Sector**

Emergency/Disaster

### **Type of Standard**

Standards Development Organization/Harmonization Effort

### **Sponsor**

Department of Homeland Security, Science and Technology Directorate

### **Purpose**

The American National Standards Institute's Homeland Security Standards Panel (ANSI-HSSP) has as its mission to identify existing consensus standards, or, if none exist, assist the Department of Homeland Security (DHS) and those sectors requesting assistance to accelerate development and adoption of consensus standards critical to homeland security. ANSI-HSSP is to catalog, promote, accelerate, and coordinate the timely development of consensus standards within the national and international voluntary standards systems intended to meet identified homeland security needs and communicate the existence of such standards appropriately to governmental units and the private sector.

### **Version**

Not applicable, as this is a standards development organization/harmonization effort

### **Year Current Version Was Adopted**

Not applicable, as this is a standards development organization/harmonization effort

### **Age of Standard**

ANSI-HSSP was established in 2003

### **Federal Involvement/Endorsement**

Department of Homeland Security: The Panel supports the work of the DHS Science and Technology Directorate's Office of Standards.

### **Who Uses**

Homeland security-related organizations

### **Mandatory/Voluntary (and Authorization)**

The standards are expected to be voluntary.



### **Estimate of Adoption**

Not applicable, as this is a standards development organization/harmonization effort

### **Standards Development Process**

ANSI-HSSP is an American National Standards Institute (ANSI) standards development organization and therefore follows ANSI's open and consensus-based process for standards development. Participation in the ANSI-HSSP is open to representatives of industry, government, professional societies, trade associations, standards developers, and consortia groups directly involved in U.S. Homeland Security standardization.

### **Type of Content**

Homeland security standards

### **Unit of Collection**

Not applicable, as this is a standards development organization/harmonization effort

### **Data Availability**

Not applicable, as this is a standards development organization/harmonization effort

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Not applicable, as this is a standards development organization/harmonization effort

### **Key Documents and Reports**

Unknown

### **Web Site**

ANSI-HSSP Web site: [http://www.ansi.org/standards\\_activities/standards\\_boards\\_panels/hssp/overview.aspx?menuid=3](http://www.ansi.org/standards_activities/standards_boards_panels/hssp/overview.aspx?menuid=3)





### **For More Information**

Jessica Carl  
Program Administrator, ANSI-HSSP  
American National Standards Institute  
25 West 43rd Street, Fourth Floor  
New York, NY 10036  
Telephone: (212) 642-4903  
Facsimile: (212) 840-2298  
E-mail: [jcarl@ansi.org](mailto:jcarl@ansi.org)

Dr. Bert Coursey, Standards Executive  
Science and Technology Directorate  
U.S. Department of Homeland Security  
Telephone: (202) 254-5811  
E-mail: [bert.coursey@dhs.gov](mailto:bert.coursey@dhs.gov)

### **Reviewed**

No





# Common Alerting Protocol (CAP)

## **Sector**

Emergency/Disaster

## **Type of Standard**

Data Interoperability Standard

## **Sponsor**

OASIS Emergency Management TC

## **Purpose**

The Common Alerting Protocol (CAP) is a simple but general format for exchanging all-hazard emergency alerts and public warnings over all kinds of networks. CAP allows a consistent warning message to be disseminated simultaneously over many different warning systems, thus increasing warning effectiveness while simplifying the warning task. CAP also facilitates the detection of emerging patterns in local warnings of various kinds, such as might indicate an undetected hazard or hostile act. CAP functions both as a standalone protocol and as a payload for EDXL messages.

## **Version**

Version 1.1

## **Year Current Version Was Adopted**

2005

## **Age of Standard**

2004

## **Federal Involvement/Endorsement**

The Department of Homeland Security, Federal Emergency Management Agency (FEMA) has announced its intention to adopt during the first quarter of calendar year 2009, an alerting protocol in line with Common Alerting Protocol (CAP) 1.1 as the standard for the Integrated Public Alert and Warnings System (IPAWS). Other CAP implementors include the U.S. Department of Homeland Security; U.S. National Weather Service; U.S. Geological Survey, California Office of Emergency Services; and many others.

## **Who Uses**

Emergency management agencies



## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

Worldwide

## **Standards Development Process**

CAP is an OASIS standard. OASIS Standards are developed through an open process, one that provides for fairness, transparency, and full participation from the entire community.

## **Type of Content**

CAP messages are self-describing; they may contain unique identification numbers, references to other CAP messages, information on status and time sent, source, digital encryption, and signature techniques. Specific event data may be contained in multiple informational segments describing urgency, severity, and certainty. Using CAP, an event may be assigned to a category (for example, geophysical, meteorological, safety, security, rescue, fire, health, environmental, transportation, infrastructure). CAP also supports digital images and audio.

## **Unit of Collection**

Per alert

## **Data Availability**

Unknown

## **Relationship to other Standards**

CAP is a part of the Emergency Data Exchange Language (EDXL) suite.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

CAP Documentation: [http://www.oasis-open.org/committees/download.php/15135/emergency-CAPv1.1-Corrected\\_DOM.pdf](http://www.oasis-open.org/committees/download.php/15135/emergency-CAPv1.1-Corrected_DOM.pdf)





## Web Site

OASIS Emergency Management TC Web site: [http://www.oasis-open.org/committees/tc\\_home.php?wg\\_abbrev=emergency](http://www.oasis-open.org/committees/tc_home.php?wg_abbrev=emergency)

For More Information

Mary McRae

OASIS Staff Contact

E-mail: [mary.mcrae@oasis-open.org](mailto:mary.mcrae@oasis-open.org)

Reviewed

No







## Coordinated Assistance Network Standard (CAN XML)

### Sector

Emergency/Disaster

### Type of Standard

Data Interoperability Standard

### Sponsor

The American Red Cross on behalf of the Coordinated Assistance Network

### Purpose

The Coordinated Assistance Network (CAN) helps communities prepare for, and respond to, disasters. The ability to exchange up-to-date information about resources is central to an effective response so that case managers have information at their fingertips to assist clients in need during a disaster. To facilitate the exchange of resource data, CAN has developed the CAN XML that specifies a minimum data set for patient and community services that can be easily and quickly shared during a disaster.

### Version

In development

### Year Current Version Was Adopted

In development

### Age of Standard

In development

### Federal Involvement/Endorsement

None

### Who Uses

Organizations responding to disasters/emergencies

### Mandatory/Voluntary (and Authorization)

Voluntary

### Estimate of Adoption

In development



### **Standards Development Process**

CAN has assembled representatives from its membership, technology experts, and others to develop the standard.

### **Type of Content**

Information about client and family, disaster experience, contact information, identifying numbers, eligibility for emergency programs

### **Unit of Collection**

Family

### **Data Availability**

In development

### **Relationship to other Standards**

The CAN XSD is being developed in collaboration with HUD's HMIS and AIRS' XSD developers.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

In development

### **Key Documents and Reports**

In development

### **Web Site**

Coordinated Assistance Network Web site: <http://www.can.org>





**For More Information**

Cristina Vetrano

Project Manager - Implementation

Disaster Services

American Red Cross

Telephone: (202) 286-3035

E-mail: [VetranoC@usa.redcross.org](mailto:VetranoC@usa.redcross.org)

**Reviewed**

No





## Disaster Surveillance Forms

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

The Centers for Disease Control and Prevention's (CDC) Disaster Surveillance Workgroup (DSWG) has developed forms for public health surveillance after a disaster. Individuals completing these forms should submit them to the appropriate state or local public health authorities. State or local public health authorities are invited to modify contact information on these forms as needed for reporting within their jurisdiction. CDC is interested in receiving completed forms after they have been submitted to, or reviewed by, state or local agencies. The information derived through these surveillance efforts is used to identify events of public health concern among facilities and across states. Information from the surveillance also assist in directing interventions and other resources to areas of greatest need, as well as guide future response efforts.

### Version

2

### Year Current Version Was Adopted

2008

### Age of Standard

2007

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention



## Who Uses

State or local public health authorities. Data collectors vary depending on the form:

- Environmental Health Shelter Assessment Tool—environmental health practitioners
- Disaster-Related Mortality Surveillance Form—medical examiners, coroners, hospitals, nursing home, or funeral homes
- Natural Disaster Morbidity Report Form (Interim)—acute care facilities (for example, shelters with medical staff, hospitals)
- Abbreviated Natural Disaster Morbidity Report Form (Interim)—hospitals
- Individual Natural Disaster Morbidity Tally Form (Interim)—shelter facilities
- Aggregate Natural Disaster Morbidity Report Form (Interim)—acute care facilities (for example, shelters with medical staff, hospitals)

## Mandatory/Voluntary (and Authorization)

Voluntary

## Estimate of Adoption

Use of the form is voluntary. Several states have adopted the use of these forms and used them during the 2008 Hurricane season.

## Standards Development Process

The forms were developed by the CDC Disaster Surveillance Workgroup, which is a cross agency working group tasked with creating standardized forms to be used following a natural disaster. External partners from the DSWG included state and local public health staff and federal partners (including American Red Cross, U.S. Public Health Service, and Department of Defense). Changes to the standards are regulated through the DSWG leadership.

## Type of Content

The CDC has the following forms:

**Environmental Health Shelter Assessment Tool**—to assist environmental health practitioners in conducting a rapid assessment of shelter conditions during emergencies and disasters. The assessment form covers 14 general areas of environmental health, ranging from basic food safety and water quality to pet (companion animal) wellness and allows for the documentation of immediate needs in shelters.

**Disaster-Related Mortality Surveillance Form**—to identify the number of deaths related to the disaster and provide basic mortality information. Setting: Form should be filled out by medical examiners, coroners, hospitals, nursing home, or funeral homes during a disaster. This form does not replace the death certificate.





**Natural Disaster Morbidity Report Form (Interim)**—to capture individual-level active surveillance of medical conditions when timely, detailed, patient-level information is needed for response efforts.

Setting: Acute care facilities (for example, shelters with medical staff, hospitals).

**Abbreviated Natural Disaster Morbidity Report Form (Interim)**—an abbreviated version of the Natural Disaster Morbidity Report Form. Use this form if summary or less-detailed information is sufficient or when the burden of collecting detailed, individual information is substantial. Setting: Hospitals

**Individual Natural Disaster Morbidity Tally Form (Interim)**—an abbreviated version of the Natural Disaster Morbidity Report Form. Use this form if summary or less-detailed information is sufficient and a tally sheet is the most useful to capture morbidity data. This form captures morbidity data at the individual level but does not separate data by individual. Setting: Shelter facilities.

**Aggregate Natural Disaster Morbidity Report Form (Interim)**—to collect aggregate morbidity data. This form should be used for reporting purposes and does not capture individual-level data. Setting: Acute care facilities (for example, shelters with medical staff, hospitals)

### Unit of Collection

The units of collection for the forms are:

- Environmental Health Shelter Assessment Tool—shelters
- Disaster-Related Mortality Surveillance Form—individual
- Natural Disaster Morbidity Report Form (Interim)—individual
- Abbreviated Natural Disaster Morbidity Report Form (Interim)—individual
- Individual Natural Disaster Morbidity Tally Form (Interim)—individual level, but does not separate data by individual
- Aggregate Natural Disaster Morbidity Report Form (Interim)—aggregate morbidity data

### Data Availability

Data collected based on these forms is owned by the local jurisdiction where the data was collected.

### Relationship to other Standards

Unknown

### Future Plans

The DSWG continues to update these standardized forms. The DSWG meets regularly with its stakeholders (federal and local public health partners) to assess and modify the forms.

### Vendors Incorporating In Products

None





## **Key Documents and Reports**

Forms may be found at: <http://www.emergency.cdc.gov/disasters/surveillance>

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention Public Health Surveillance After a Disaster Web site: <http://www.emergency.cdc.gov/disasters/surveillance>

## **For More Information**

Amy Wolkin, MSPH, Acting Lead  
Preparedness and Response Team, Health Studies Branch  
Centers for Disease Control and Prevention  
4770 Buford Highway, MS F57  
Atlanta, GA 30341  
Telephone: (770) 488-3402  
Facsimile: (770) 488-3450  
E-mail: [awolkin@cdc.gov](mailto:awolkin@cdc.gov)

## **Reviewed**

Yes





# Emergency Data Exchange Language (EDXL)

## Sector

Emergency/Disaster

## Type of Standard

Data Interoperability Suite of Standards

## Sponsor

A Memorandum of Agreement between the U.S. Department of Homeland Security and the Emergency Interoperability Consortium outlines the initiative. The Disaster Management eGov Initiative (managed by DHS' Disaster Management Program) is providing organizational resources and technical support. The involvement of all emergency practitioner groups is encouraged. The ComCARE Alliance has been tasked by DHS to facilitate these groups' participation.

## Purpose

The Emergency Data Exchange Language (EDXL) is a suite of several independent OASIS standards which facilitate emergency information sharing and data exchange across the local, state, tribal, national and nongovernmental organizations of different professions that provide emergency response and management services. The effort focuses on standardization of specific messages (messaging interfaces) to facilitate emergency communication and coordination, particularly when more than one profession is involved.

- **Common Alerting Protocol (CAP):** It provides the ability to exchange all-hazard emergency alerts, notifications, and public warnings, which can be disseminated simultaneously over many different warning systems (for example, computer systems, wireless, alarms, TV, radio). CAP is the most widely known and implemented emergency response messaging standard.
- **Distribution Element (DE):** DE provides flexible message-distribution framework for emergency information systems data sharing. Messages may be distributed by specific recipients, by a geographic area, or by other codes such as agency type (police, fire, and so forth).
- **Resource Messaging (RM):** EDXL-RM describes a suite of standard XML messages for data sharing among emergency and other information systems that deal in requesting and providing emergency equipment, supplies, people, and teams.
- **Hospital AVailability Exchange (HAVE):** HAVE specifies an XML document format that allows the communication of the status of a hospital, its services, and resources, including bed capacity and availability, emergency department status, and available service coverage.
- **Situation Reporting:** SitReps provides a standard XML format for sharing information across the disparate systems of any public or private organization and Emergency Support Function (ESF) about a situation, incident, or event and the operational picture of current and required



response. EDXL-SitRep purpose is to guide more effective preparation, response, management, and recovery through seamless information-sharing before, during, and after emergencies and disasters of any scale or type of hazard.

- **Emergency Patient Tracking:** EPT provides a standard XML format for sharing patient location and treatment information from the scene of an incident until admitted into a care facility. EDXL-EPT purpose is to guide more effective patient care by sharing information about patient physical location, condition, and treatments and routing patients to the proper facilities to receive the correct level of continued treatment.

## Version

- **Common Alerting Protocol (CAP):** CAP 1.1
- **Distribution Element (DE):** DE 1.0
- **Resource Messaging (RM):** RM 1.0
- **Hospital Availability Exchange (HAVE):** HAVE 1.0
- **Situation Reporting:** under development
- **Emergency Patient Tracking:** under development

## Year Current Version Was Adopted

- **Common Alerting Protocol (CAP):** 2005
- **Distribution Element (DE):** 2006
- **Resource Messaging (RM):** 2008
- **Hospital Availability Exchange (HAVE):** 2008
- **Situation Reporting:** under development
- **Emergency Patient Tracking:** under development

## Age of Standard

- **Common Alerting Protocol (CAP):** 2004
- **Distribution Element (DE):** 2006
- **Resource Messaging (RM):** 2008
- **Hospital Availability Exchange (HAVE):** 2008
- **Situation Reporting:** under development
- **Emergency Patient Tracking:** under development

## Federal Involvement/Endorsement

The Office for Interoperability and Compatibility (OIC) is a communications program in the Department of





Homeland Security's (DHS) Science and Technology Directorate. Following various voice interoperability programs such as SAFECOM, the OIC's interoperable messaging standards program was initiated as an e-government initiative. Its mission is to serve as the standards program within the federal government to help local, tribal, state, and federal public safety and emergency response agencies improve public safety response through more effective and efficient interoperable data sharing. The OIC standards program is providing organizational resources and technical support and sponsors a Practitioner Steering Group (PSG) and Standards Working Group (SWG) which defines priorities and requirements for new standards. The involvement of all emergency practitioner groups is encouraged.

Practitioner requirements are submitted to a Standards Development Organization (typically OASIS) for development of public, international standards. A Memorandum of Agreement between the U.S. Department of Homeland Security and the Emergency Interoperability Consortium also outlines relationships with the vendor communities.

### **Who Uses**

Local, state, tribal, national/federal, and nongovernmental organizations of different professions that provide emergency response and management services

### **Mandatory/Voluntary (and Authorization)**

Voluntary—endorsed by the National Incident Management System (NIMS)

Authority for the MOA comes from Sections 102(g) and 502 of the Homeland Security Act, Public Law 107-296

### **Estimate of Adoption**

CAP – Widely adopted internationally

DE – Growing adoption

HAVE and RM – Implementers just beginning

SitReps and EPT – not applicable as they are not yet approved

### **Standards Development Process**

The EDXL initiative is a national effort including a diverse and representative group of local, state, and federal emergency response organizations and professionals, following a multi-step process. The EDXL Practitioners group drives priorities and requirements for specific EDXL messages sets and messaging components. The standards development effort is simplified and summarized below:

- Step 1 : Initial meeting of practitioners to define and prioritize requirements
- Step 2: Iterative discussion and development of draft specification by the Standards Working Group



- Step3: Limited trials and demonstrations by technology companies to validate and vet the technical feasibility
- Step 4: Endorsement by the responsible executive committees and other strategic committees
- Step 5: Submission of the specification to the appropriate standards organization

### **Type of Content**

EDXL is a cooperative effort to define a NIMS-compliant family of shared data exchange specifications encompassing: Incident Notification and Situation Reports; Status Reporting; Resource Requests and Dispatch; Analytical Data; Geospatial Information; and Identification and Authentication. EDXL is intended to comprise three layers of data exchange standards utilizing XML data syntax and services:

- EDXL Vocabulary: Specified data elements and taxonomies to apply common terminology to data sharing regarding emergency incidents, conditions, resources, activities, and outcomes. This will draw heavily on current common-vocabulary efforts (Justice Data Dictionary, FEMA resource typing, NIMS, and so forth) and the XML standards cited above. This project will support emergency organizations reviewing the XML and taxonomy work product of other professions to find commonalities (the ‘common terms’ project).
- EDXL Messages: Develop formats for messages (XML documents) using the EDXL Vocabulary to implement routing of emergency messages (a draft ‘header’ has been produced, trialed, and submitted for standards approval) and business processes such as emergency response resources reports, queries, updates, cancellations, and error handling. The current focus is on resource messages.
- EDXL Interfaces: Technical protocols and formats for routing of EDXL messages over various kinds of data networks and systems, based on SOAP and Web-services standards, but generalized for use in a wide variety of communications environments. The goal is to make it simple and straightforward for vendors to write interfaces from their products to EDXL.

### **Unit of Collection**

Varies

### **Data Availability**

Depends upon implementation

### **Relationship to other Standards**

A design principle for EDXL is adopting, promoting, and spreading the work that has already been done to other professions (particularly with the very extensive NIEM dictionary). Standards coordination is ongoing between EDXL and HITSP.





## Future Plans

Additional message needs will be addressed as the Practitioners raise the need for them. The objective is to rapidly deliver implementable standard messages in an incremental fashion directly to emergency response agencies in the trenches, providing seamless communication and coordination supporting each particular process. The Practitioner Steering Group (PSG) is submitting the next standard “Situation Reporting” to OASIS during Q1 of 2009 and developing scope and draft requirements for the next EDXL standard: “Emergency Patient Tracking.”

## Vendors Incorporating In Products

- NASA
- United States Geological Survey (USGS)
- Los Angeles Fire, Police, and Sheriff’s Departments
- National Guard Bureau
- Hormann of America
- United State Geological Survey (USGS)
- NOAA HazCollect
- Capitol Area Wireless Integrated Network (CapWin)
- Northern Command (NorthCom)
- National Capitol Region (NCR) – Washington, DC
- DHS S&T Integrated Chemical, Biological, Explosive, Radiological, and Nuclear (ICBRNE) Detection System Demonstration
- City and County of Los Angeles
- International Telecommunications Union (ITU) adopting CAP for global alerting
- International Tsunami Warning System implementing CAP
- FCC mandated CAP as part of the Emergency Alert System (EAS)\
- Many vendors

## Key Documents and Reports

EDXL Frequently Asked Questions: [http://www.comcare.org/uploads/EDXL\\_FAQs.pdf](http://www.comcare.org/uploads/EDXL_FAQs.pdf)

U.S. Department of Homeland Security and the Emergency Interoperability Consortium Memorandum of Agreement: <http://xml.coverpages.org/edxl.html#MOA-Extract>

## Web Site

<http://www.oasis-open.org/home/index.php>

OASIS EDXL Web site: <http://xml.coverpages.org/edxl.html>



Emergency Data Exchange Language (EDXL) Distribution Element, v. 1.0 Specification:  
<http://xml.coverpages.org/EDXL-DEv10-Standard20060501.pdf>

COMCARE Emergency Response Alliance Web site: <http://www.comcare.org/edxl.html>

**For More Information**

Denis A. Gusty, PMP  
Program Manager  
Office for Interoperability and Compatibility  
Science and Technology Directorate  
Department of Homeland Security  
Washington, DC 20528  
Telephone: (202) 254-5647

Tim Grapes  
Evolution Technologies, Inc.  
Telephone: (703) 654-6075  
Facsimile: (703) 654-6001/(703) 304-4829  
E-mail: [tgrapes@evotecinc.com](mailto:tgrapes@evotecinc.com)

**Reviewed**

Yes





## Epidemic Information Exchange (Epi-X)

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

Epi-X is a Web-based communications solution for public health professionals. Through Epi-X, CDC officials, state and local health departments, poison control centers, and other public health professionals can access and share preliminary health surveillance information—quickly and securely. Users can also be actively notified of breaking health events as they occur. Epi-X offers scientific and editorial support, controlled user access, digital credentials and authentication, rapid outbreak reporting, and peer-to-peer consultation.

### Version

2000

### Year Current Version Was Adopted

2000

### Age of Standard

2000

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Who Uses

Participation in Epi-X is limited to public health officials designated by each health agency. These experts are engaged in identifying, investigating, and responding to health threats.

### Mandatory/Voluntary (and Authorization)

Voluntary





### **Estimate of Adoption**

Epi-X has approximately 4,200 users. Since its inception in December 2000, health officials have posted approximately 6,700 reports.

### **Standards Development Process**

Unknown

### **Type of Content**

Epi-X supports postings about disease outbreaks and other public health events that potentially involve multiple jurisdictions. Epi-X highlights include reports related to local and national responses to terrorism, SARS, and Hurricane Katrina. Other Epi-X reports have focused on West Nile virus surveillance, influenza surveillance and pandemic preparation, foodborne outbreaks and food recalls that affected residents in multiple states, and investigations of travelers with contagious illnesses.

### **Unit of Collection**

Unknown

### **Data Availability**

Access to Epi-X is limited to designated officials to ensure the security necessary for the exchange of preliminary and provisional information. Epi-X users are designated by each state. Each official must obtain pre-approval from the appropriate health agency.

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Unknown

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention Epi-X Web site:  
<http://www.cdc.gov/epix>





**For More Information**

Robbie Michelle Locklar

Epi-X Training and Support

CDC Epidemic Information Exchange (Epi-X)

U.S. Centers for Disease Control and Prevention

Coordinating Center for Health Information and Service

National Center for Health Marketing

Telephone: (404) 639-5049 or (866) 720-3749

E-mail: [epix@cdc.gov](mailto:epix@cdc.gov)

**Reviewed**

No





## Health Alert Network (HAN)

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

The Health Alert Network (HAN) is intended to ensure that each community has rapid and timely access to emergent health information; a cadre of highly trained professional personnel; and evidence-based practices and procedures for effective public health preparedness, response, and service on a 24/7 basis.

The Health Alert Network will function as PHIN's Health Alert component. This includes collaborating with federal, state, and city/county partners to develop protocols and stakeholder relationships that will ensure a robust interoperable platform for the rapid exchange of public health information.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

1998

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Who Uses

Connected To HAN: 50 States, 3 large City Health Departments, 3 County Health Departments, 8 Territories, the District of Columbia, Health Organizations and Major Hospital Networks, local exemplar centers, academic centers, and specialty centers



## **Mandatory/Voluntary (and Authorization)**

Voluntary

All 50 states have funding for HAN goals pertaining to focus area “E” of the cooperative agreements

## **Estimate of Adoption**

A vast majority of the state-based HAN programs have over 90 percent of their population covered under the umbrella of HAN.

## **Standards Development Process**

The CDC is collaborating with federal, state, and city/county partners to develop protocols and stakeholder relationships that will ensure a robust interoperable platform for the rapid exchange of public health information.

## **Type of Content**

Unknown

## **Unit of Collection**

Unknown

## **Data Availability**

Unknown

## **Relationship to other Standards**

HAN will continue to be an active asset in the overall PHIN Initiative.

## **Future Plans**

HAN will continue to be an active asset in the overall PHIN Initiative.

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Unknown

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Health Alert Network Web site: <http://www2a.cdc.gov/han/Index.asp>



**For More Information**

Robb Chapman (CDC/CCHIS/NCPHI)  
National Center for Public Health Informatics  
Centers for Disease Control and Prevention  
1600 Clifton Road, MS E-68  
Atlanta, GA 30333  
Telephone: (404) 498-6386  
Facsimile: (404) 498-6225  
E-mail: [rsc0@cdc.gov](mailto:rsc0@cdc.gov)

**Reviewed**

No





# National Electronic Disease Surveillance System (NEDSS)

## Sector

Emergency/Disaster  
Public Health

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Integrated Health Information Systems in the Office of Director

## Purpose

The National Electronic Disease Surveillance System (NEDSS) is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state, and local levels. It is a major component of the Public Health Information Network (PHIN). NEDSS system architecture is designed to integrate and replace several current CDC surveillance systems, including the National Electronic Telecommunications System for Surveillance (NETSS), the HIV/AIDS reporting system, and the vaccine preventable diseases and systems for tuberculosis (TB) and infectious diseases.

## Version

In development

## Year Current Version Was Adopted

In development

## Age of Standard

NEDSS began in 2001

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Integrated Health Information Systems in the Office of Director

## Who Uses

Healthcare and public health organizations



**Mandatory/Voluntary (and Authorization)**

Voluntary

NEDSS, along with the Public Health Emergency Preparedness Cooperative Agreement, provides major financial support directly to state and local public health surveillance systems to develop or purchase integrated NEDSS-compatible applications.

Estimate of Adoption

Over 35 states have implemented surveillance systems based on the NEDSS vision,

**Standards Development Process**

NEDSS is a collaborative effort among state and local public health partners and numerous CDC staff and contractors. The success of NEDSS is dependent upon the assistance and expertise of these partners and the coordinated efforts of diverse scientific and public health disciplines. Using software development industry standards, formal processes for identifying the public health needs in the system (business requirements) are developed through Joint Application Development (JAD) sessions that involve all principal stakeholders which include state and local public health representatives associated with such national bodies as: The Council of State and Territorial Epidemiologists, The Association of State and Territorial Health Officials, The National Association of City and County Health Officials, The Association of Public Health Laboratories, The National Association of Public Health Statistics and Information Systems, The National Association of Health Data Organizations, and similar entities representing the needs of particular programmatic areas.

**Type of Content**

Unknown

**Unit of Collection**

Individual

**Data Availability**

In development

**Relationship to other Standards**

NEDSS system architecture is designed to integrate and replace several current CDC surveillance systems, including the National Electronic Telecommunications System for Surveillance (NETSS), the HIV/AIDS reporting system, and the vaccine preventable diseases and systems for tuberculosis (TB) and infectious diseases.

NEDSS relies heavily on industry standards (including standard vocabulary code sets such as LOINC, SNOWMED, and HL7).





## **Future Plans**

NEDSS will support standards-based PHIN and AHIC-approved electronic message exchange between public health stakeholders.

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Base System Description—describes the vision, development, implementation, and uses of the NEDSS Base System as a component of the overall NEDSS initiative: <http://www.cdc.gov/nedss/BaseSystem/NEDSSBaseSysDescription.pdf>

Base System Fact Sheet: <http://www.cdc.gov/nedss/BaseSystem/NEDSSBasesysFactSheet.pdf>

System Specifications: <http://www.cdc.gov/nedss/BaseSystem/NEDSSRequirements.pdf>

System Architecture—Version 2.0 of the “Proposed Integrated Surveillance Systems Component Architecture”: <http://www.cdc.gov/nedss/BaseSystem/NEDSSsysarch2.0.pdf>

System Reference Tables: [http://www.cdc.gov/nedss/BaseSystem/Sys\\_Ref\\_Tables\\_101001.pdf](http://www.cdc.gov/nedss/BaseSystem/Sys_Ref_Tables_101001.pdf)

Business Discovery Statement—contains information regarding the NEDSS Base System and Program Area Modules (PAMs). Its purpose is to guide decisions regarding project scope, processes supported, and functionality for the project. The program area public health processes and the overall NEDSS vision provide the context for the Business Discovery Statement: [http://www.cdc.gov/nedss/BaseSystem/NEDSSBusinessDiscoveryStatement1\\_2.pdf](http://www.cdc.gov/nedss/BaseSystem/NEDSSBusinessDiscoveryStatement1_2.pdf)

Business Process Groups—documents, at a high level, the public health business processes that are within the scope of the NEDSS project. It documents what processes are targeted in the initial release of the system and which processes will be addressed in subsequent releases: <http://www.cdc.gov/nedss/BaseSystem/BusinessProcessGroups.pdf>

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention NEDSS Web site: <http://www.cdc.gov/nedss>



**For More Information**

Claire Broome, MD

Senior Advisor to the Director

Integrated Health Information Systems

Centers for Disease Control and Prevention

2960 Brandywine Road, Mailstop D68

Atlanta, GA 30341

E-mail: [cbroome@cdc.gov](mailto:cbroome@cdc.gov)

**Reviewed**

No





## National Information Exchange Model (NIEM)

### Sector

Community Resources  
Corrections  
Criminal Justice/Courts  
Emergency/Disaster

### Type of Standard

Overarching Framework  
Data Interoperability Standards

### Sponsor

National Information Exchange Model (NIEM) is a joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice with outreach to other departments and agencies.

### Purpose

NIEM is designed to develop, disseminate, and support enterprisewide information exchange standards and processes that can enable jurisdictions to effectively share critical information in emergency situations, as well as support the day-to-day operations of agencies throughout the nation.

### Version

NIEM 2.0

### Year Current Version Was Adopted

2007

### Age of Standard

2005

### Federal Involvement/Endorsement

Joint venture between the U.S. Department of Homeland Security and the U.S. Department of Justice, as well as supported by the Global Justice Information Sharing Initiative. There have also been discussions with other interest groups that are expected to result in broader involvement. For example, the U.S. Department of the Navy has begun to partner with NIEM to address maritime domain information sharing requirements.

### Who Uses

All levels of government and industry to ensure homeland security and public safety, including: law



enforcement; courts; prosecution; corrections; emergency management; fire and EMS; immigration; customs; international trade; transportation security; intelligence; and family services (juvenile justice, child welfare, and child support)

### **Mandatory/Voluntary (and Authorization)**

NIEM is recognized as a voluntary standard, built by a national consensus process by which the user communities are directly involved in the development of the data model. Therefore, DOJ and DHS support NIEM adoption by providing special conditions in certain grants that require the use of NIEM when applicable, thus promoting larger scale adoption and use of the practitioner-driven model.

NIEM is supportive of the Homeland Security Presidential Directive (HSPD-5), which assigns the Secretary of the Department of Homeland Security the role of principal federal official for domestic incident management. The Homeland Security Act of 2002 charges the Secretary with the responsibility for coordinating federal operations within the United States to prepare for, respond to, and recover from terrorist attacks, major disasters, and other emergencies. Building on this foundation is a series of Executive Orders which direct agencies to improve the exchange of terrorism information and protect their ability to acquire information.

### **Estimate of Adoption**

NIEM adoption has been required at the federal level through the CIO organizations of DOJ (through One-DOJ and LEISP) and DHS (through the Enterprise Data Management Office). Numerous projects within both Departments are currently based on NIEM as a data exchange platform. NIEM is being adopted statewide in several instances, including New York, Florida, Minnesota, and Texas; and dozens of local and regional projects, in at least 36 states, have been identified as well.

### **Standards Development Process**

NIEM is a multiagency information sharing program. Intergovernmental groups representing key stakeholders play an important role in creating and sustaining partnerships. Partners can share knowledge and resources across the government and ensure that NIEM provides true value to citizens. Because of the inherent complexity of issues and jurisdictional control, an organizational structure is a necessary first step to ensure that the stakeholders are intimately involved in the project. These NIEM governance bodies include the Executive Steering Committee, Policy Advisory Panel, NIEM Program Management Office, and several working-level committees focused on technical and business requirements and communications and outreach. The NIEM Executive Steering Committee represents key public decision makers from DOJ, DHS, and the Global Justice Information Sharing Initiative, as well as their constituents, who have a significant vested interest in NIEM objectives. The Executive Steering Committee provides strategic direction to the Program Management Office, whose responsibilities are to oversee the implementation and development of NIEM.





## **Type of Content**

Data exchange standards for information that is commonly shared across the broad justice, public safety, emergency and disaster management, intelligence, and homeland security enterprises

NIEM in whole consists of several key parts. The most often referenced is the data model, comprised of over 7,000 standard element names, presented as xml tags. The second is a data dictionary, providing a standard, operational definition for each of those elements. Third, NIEM presents a broad suite of tools to assist in discovery and use of the model. Finally, NIEM also includes a standardized methodology for implementing NIEM, the Information Exchange Package Documentation (IEPD) specification. This IEPD specification prescribes a life cycle methodology for the development of information exchanges, which is grounded in subject matter expertise; it also prescribes a standard means of constructing the xml schema by defining the finite subset of NIEM data elements that will be used for a particular exchange. These tools and specifications help to ensure rapid adoption and facilitate reuse of existing work (saving time, energy, and money otherwise spent “reinventing the wheel” across implementations).

## **Unit of Collection**

The current domains in NIEM include justice, intelligence, immigration, emergency management, international trade, and infrastructure protection. NIEM includes xml tags that serve as standard element names as well as standard definitions for over 7,000 individual data elements. NIEM does not itself collect data—it is better conceived as a standard that includes standardized metadata.

## **Data Availability**

NIEM as a program does not own any data; it simply defines the format and structure of a data exchange model.

## **Relationship to other Standards**

NIEM leverages the data exchange standards efforts successfully implemented by the Global Justice Information Sharing Initiative and extends the Global Justice XML Data Model (GJXDM) to facilitate timely and secure information sharing across the whole of the justice, public safety, emergency and disaster management, intelligence, and homeland security domains. It also references existing standards, including the ANSI-NIST standard for fingerprint and other biometric data, as well as the Emergency Data Management (EDXL) messaging standard for emergency response.

In addition, the justice community has developed messaging standards to ease architectural specification and implementation. The Logical Entity eXchange Specification (LEXS) builds on top of NIEM and assists in message routing and data rendering, and the Justice Reference Architecture (JRA) provides a Service-Oriented Architecture framework that leverages NIEM as the data payload.



## Future Plans

NIEM efforts will concentrate on:

- **Core Capability Development and Maintenance:** This effort focuses on delivering NIEM 2.0 and subsequent releases; fully implementing NIEM governance; representing the critical mass of justice, homeland security, and intelligence information exchanges in their associated domains; developing a tools roadmap based on user requirements and delivering the tools into operation; and launching outreach activities (including the Web site), conference presentations, and training.
- **Information Exchange Standard Development:** This effort focuses on developing families of Information Exchange Package Documentation (IEPD) representing core, priority business areas at the national level. The initial focus areas will include incident reporting, people screening, suspicious activities, cargo screening, emergency and disaster management, and case management. Policies and processes will be developed to support creating, modifying, and implementing these standards. Nothing in this statement precludes communities of interest (COIs) from championing and developing information exchange standards within their domains or for multiple COIs to do so cooperatively, with direct sponsorship from the NIEM PMO. They will follow the NIEM IEPD development process.
- **Outreach and Implementation:** This effort focuses on identifying additional pilots at the local, state, and tribal levels, targeting the emerging information exchange standards mentioned above and implementing the infrastructure needed for training and technical assistance, including a help desk.
- **Additional domains being addressed for the next release** include Maritime Domain Awareness, Child and Family Services, and others.

## Vendors Incorporating In Products

Like federal, state, local, and tribal adoption and use, the incorporation of NIEM into private-sector, third-party products is difficult to estimate. The effort is supported by the Integrated Justice Information Systems Institute (IJIS): “a nonprofit membership organization ...[composed primarily] of information technology companies and consultancies that provide products or services to the justice, public safety, and homeland security sectors for the purpose of helping these communities share information.” ([www.ijis.org](http://www.ijis.org))

## Key Documents and Reports

Executive Message: [http://www.niem.gov/files/NIEM\\_Executive\\_Briefing.pdf](http://www.niem.gov/files/NIEM_Executive_Briefing.pdf)

NIEM Introduction Manual: [http://www.niem.gov/files/NIEM\\_Introduction.pdf](http://www.niem.gov/files/NIEM_Introduction.pdf)

NIEM User Guide: [http://www.niem.gov/pdf/NIEM\\_User\\_Guide.pdf](http://www.niem.gov/pdf/NIEM_User_Guide.pdf)

The NIEM specification and a variety of documents and downloads: <http://www.niem.gov/library.php>





### **Web Site**

NIEM Web site: <http://www.niem.gov/>

### **For More Information**

Christopher Traver

Senior Policy Advisor

Bureau of Justice Assistance

U.S. Department of Justice

810 Seventh Street NW

Washington, DC 20531

Telephone: (202) 307-2963

Facsimile: (202) 307-0036

E-mail: [christopher.traver@usdoj.gov](mailto:christopher.traver@usdoj.gov)

### **Reviewed**

Yes





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# EMPLOYMENT/ WORKFORCE TRAINING





# Workforce Investment Act Data Reporting and Validation System (DRVS)

## Sector

Employment/Workforce Training

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Labor, Employment and Training Administration

## Purpose

Data Reporting and Validation System (DRVS) enables states to complete the technical specifications for preparation of their annual performance reports and standardized record data.

## Version

7.0

## Year Current Version Was Adopted

Unknown

## Age of Standard

Unknown

## Federal Involvement/Endorsement

U.S. Department of Labor, Employment and Training Administration

## Who Uses

States to report on the following programs: Unemployment Insurance Benefits and Tax (UI), Workforce Investment Act (WIA), Trade Adjustment Assistance (TAA and NAFTA-TAA) Labor Exchange, National Farmworker Jobs Program (NFJP), Indian and Native American Programs (INA), Senior Community Service Employment (SCSEP) Office of Apprenticeship, Training, Employment, and Labor Services (OATELS).

## Mandatory/Voluntary (and Authorization)

Mandatory

The Workforce Investment Act of 1998 sets out performance and accountability requirements for grantees.



### **Estimate of Adoption**

It is expected, as a mandatory reporting program, that adoption would be high.

### **Standards Development Process**

Unknown

### **Type of Content**

Individual and program

### **Unit of Collection**

Individual and program

### **Data Availability**

Unknown

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

DRVS User's Guide:

[http://www.doleta.gov/performance/reporting/docs/WIA7\\_0/DRVS\\_WIA7\\_UsersGuide.pdf](http://www.doleta.gov/performance/reporting/docs/WIA7_0/DRVS_WIA7_UsersGuide.pdf)

### **Web Site**

Department of Labor, Employment, and Training Administration DRVS Web site:

[http://www.doleta.gov/performance/reporting/tools\\_datavalidation.cfm](http://www.doleta.gov/performance/reporting/tools_datavalidation.cfm)





**For More Information**

John Beverly, III  
Administrator  
Office of Performance and Technology  
200 Constitution Avenue NW  
Room S-5206  
Washington, DC 20210

Reviewed  
No





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# FOOD AND NUTRITION PROGRAMS







## Pediatric Nutrition Surveillance System (PedNSS)

### Sector

Child and Family Services  
Food and Nutrition  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Purpose

The Pediatric Nutrition Surveillance System (PedNSS) is a child-based public health surveillance system that monitors the nutrition of low-income children in federally funded maternal and child health programs.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

In the late 1960s, the United States Ten-State Nutrition Survey characterized the nutritional status of children from low-income families as being less than satisfactory. The findings generated concern about the nutritional status of low-income populations in the United States, especially children. Specifically, calories, calcium, iron, and vitamins A and C were less likely to be consumed in adequate amounts by low-income black and Hispanic children. In response, CDC began working with five states (Arizona, Kentucky, Louisiana, Tennessee, and Washington) in 1973 to develop a system for continuous monitoring of the nutritional status of selected high-risk population groups.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

**Who Uses**

Federally funded health clinics serving low-income children participate on a voluntary basis and report data to state-level agencies, which in turn submit data to CDC. The majority of PedNSS records (85.4 percent) are from the WIC Program. The figure below shows the distribution of records received from WIC, EPSDT, MCH, and other programs.

**Mandatory/Voluntary (and Authorization)**

PedNSS is a voluntary surveillance system. In 2007, 44 states, 1 U.S. Territory, 5 Indian Tribal Organizations, and the District of Columbia contributed data representing approximately 8 million children under 5 years of age.

**Estimate of Adoption**

In 2004, a total of 48 contributors, including 40 states, the District of Columbia, Puerto Rico, and 7 tribal governments participated in PedNSS.

**Standards Development Process**

Unknown

**Type of Content**

Demographic data collected by PedNSS include race or ethnicity, sex, migrant status, household income (where indicated), and zip code. Data collected to assess nutritional status include weight, length/height, and hemoglobin or hematocrit measurements. Weight, stature, and length are commonly used to assess the size and growth of children. Data on birthweight and breastfeeding status are collected on children from birth to 2 years of age. Health risk behavior data includes tv/video viewing and household smoking.

**Unit of Collection**

Individual (unique child records)

**Data Availability**

National data set is not available to the public, but published tables and reports are available.

**Relationship to other Standards**

PedNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program; and
- Title V Maternal and Child Health Program (MCH).

A majority of the data are from the WIC program that serves children up to age 5.





An important use of the PedNSS data is monitoring the Healthy People 2010 objectives.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

PedNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pednss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pednss_users_guide/index.htm)

2006 PedNSS Summary Report: [http://www.cdc.gov/pednss/pdfs/PedNSS\\_2006.pdf](http://www.cdc.gov/pednss/pdfs/PedNSS_2006.pdf)

National PedNSS data tables can be accessed through the following Web site:

<http://www.cdc.gov/pednss>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):

<http://www.cdc.gov/pednss/index.htm>

### **For More Information**

Division of Nutrition, Physical Activity and Obesity

National Center for Chronic Disease Prevention and Health Promotion

Centers for Disease Control and Prevention

4770 Buford Highway NE

Mail Stop K-25

Atlanta, GA 30341-3717

Telephone: (770) 488-5702

### **Reviewed**

No





## Pregnancy Nutrition Surveillance System (PNSS)

### Sector

Child and Family Services  
Food and Nutrition  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Purpose

The Pregnancy Nutrition Surveillance System (PNSS) monitors risk factors associated with infant mortality and poor birth outcomes among low-income pregnant women who participate in federally funded public health programs including Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); and Title V, the Maternal and Child Health Program (MCH).

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

PNSS has been in existence since 1979 when representatives from five states (Arizona, California, Kentucky, Louisiana, and Oregon) began working with CDC to develop a system for monitoring the prevalence of nutrition problems and behavioral risk factors related to mortality and low birthweight among infants born to high-risk pregnant women.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Who Uses

Federally funded health clinics serving pregnant women participate on a voluntary basis and report data to state-level agencies, which in turn submit the data to CDC. These data are combined for annual reporting. Approximately 99 percent of PNSS data come from the WIC Program.



## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

In 2006, 26 states, 1 U.S. territory, and 5 Indian Tribal Organizations contributed data representing approximately 1.1 million women. The number of surveillance records has increased from approximately 10,000 in 1979 to over 700,000 in 2002.

## **Standards Development Process**

Unknown

## **Type of Content**

Data on maternal health indicators include pre-pregnancy weight status, maternal weight gain, parity, interpregnancy intervals, anemia, diabetes, and hypertension during pregnancy. Data on maternal behavioral indicators include medical care, WIC enrollment, multivitamin consumption, smoking, and drinking.

## **Unit of Collection**

Individual

## **Data Availability**

Data tables can be accessed through the following Web site:

[http://www.cdc.gov/pednss/pnss\\_tables/index.htm](http://www.cdc.gov/pednss/pnss_tables/index.htm)

## **Relationship to other Standards**

PNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Title V Maternal and Child Health Program (MCH)

A majority of the data are from the WIC program that serves pregnant, breastfeeding, and postpartum women.

An important use of the PNSS data is monitoring the Healthy People 2010 objectives.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown





## **Key Documents and Reports**

PNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pnss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pnss_users_guide/index.htm)

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):  
<http://www.cdc.gov/pednss/index.htm>

## **For More Information**

Division of Nutrition, Physical Activity and Obesity  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
4770 Buford Highway NE  
Mail Stop K-25  
Atlanta, GA 30341-3717  
Telephone: (770) 488-5702

## **Reviewed**

No







# Supplemental Nutrition Assistance Program (SNAP)

**Sector**

Food and Nutrition

**Type of Standard**

Reporting Requirements or Reporting Standards

**Sponsor**

U.S. Department of Agriculture, Food and Nutrition Service

**Purpose**

SNAP provides nutrition and healthy food within reach for low-income households. The reporting standards specify what information must be collected.

**Version**

Unknown

**Year Current Version was Adopted**

Unknown

**Age of Standard**

Unknown

**Federal Involvement/Endorsement**

U.S. Department of Agriculture, Food, and Nutrition Service

**Who Uses**

States

**Mandatory/Voluntary (and Authorization)**

Mandatory

Food Stamp provisions of Title IV of Public Law 110-246, the Food, Conservation, and Energy Act of 2008 (FCEA), commonly known as the Farm Bill reauthorization.

**Estimate of Adoption**

It is expected, as a mandatory reporting program, that adoption would be high.



## **Standards Development Process**

Unknown

## **Type of Content**

Unknown

## **Unit of Collection**

Individual and programmatic

## **Data Availability**

USDA publishes annual aggregate reports.

## **Relationship to other Standards**

Unknown

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Food Stamp Program State Activity Report, 2006: [http://www.fns.usda.gov/snap/qc/pdfs/2006\\_state\\_activity.pdf](http://www.fns.usda.gov/snap/qc/pdfs/2006_state_activity.pdf)

Variety of other program and participant reports may be found at: <http://www.fns.usda.gov/OANE/MENU/published/SNAP/SNAP.htm>

## **Web Site**

U.S. Department of Agriculture, Food, and Nutrition Service SNAP Web site: <http://www.fns.usda.gov/snap>

For More Information

Jeffrey N. Cohen

Director

Benefit Redemption Division

3101 Park Center Drive

Alexandria, VA 22302

Telephone: (703) 305-2517

E-mail: [jeff.cohen@fns.usda.gov](mailto:jeff.cohen@fns.usda.gov).





## Women, Infants, and Children Program (WIC)

### Sector

Food and Nutrition Programs

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Agriculture, Food, and Nutrition Service

### Purpose

WIC provides federal grants to states for supplemental foods, healthcare referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age 5 who are found to be at nutritional risk.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

Unknown

### Federal Involvement/Endorsement

U.S. Department of Agriculture, Food, and Nutrition Service

### Who Uses

State health departments who are the administrators of state WIC programs

### Mandatory/Voluntary (and Authorization)

Mandatory

### Estimate of Adoption

It is expected, as a mandatory reporting program, that adoption would be high.



## **Standards Development Process**

Unknown

## **Type of Content**

Demographic information; nutritional risk(s) present at certification; anemia status; weight; height; breastfeeding status; participation in other social services programs; location of the WIC service site

## **Unit of Collection**

Mother and child (separately and unlinked), program

## **Data Availability**

Monthly Data—Agency Level, FY 2008: Participation by Category and Food Cost Per Person is available at: <http://www.fns.usda.gov/pd/wicmain.htm>

Variety of studies and reports are available at: <http://www.fns.usda.gov/oane/MENU/Published/WIC/WIC.htm>

## **Relationship to other Standards**

A 2004 report, Linking WIC Program Data to Medicaid and Vital Records Data: Phase II Report, Data Development Initiatives for Research on Food Assistance and Nutrition Programs—Final Report (<http://www.ers.usda.gov/publications/efan04005/efan04005-2>), outlined a proposal to create a national database that links state data from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) with Medicaid and vital records data. The linked information would create new opportunities for federal and state program administrators, as well as independent researchers, to examine a number of factors related to program participation and dynamics. The report provides an implementation plan for creating a national database, including potential costs, benefits, and alternatives. The initiative is one of three that have the potential to improve the usefulness and cost-effectiveness of research on federal food assistance and nutrition programs.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

WIC Studies: <http://www.fns.usda.gov/oane/MENU/Published/WIC/WIC.htm>

## **Web Site**

U.S. Department of Agriculture, Food, and Nutrition Service WIC homepage: <http://www.fns.usda.gov/wic>





**For More Information**

Debra Whitford, Chief  
Policy and Program Development Branch  
Supplemental Food Programs Division  
Food and Nutrition Service  
USDA  
3101 Park Center Drive, Room 528  
Alexandria, VA 22302  
Telephone: (703) 305-2746  
E-mail: [Debbie.Whitford@fns.usda.gov](mailto:Debbie.Whitford@fns.usda.gov)

**Reviewed**

No





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# HEALTH CARE







## ASC X 12N Transaction

### **Sector**

Health care

### **Type of Standard**

Data Interoperability Standard

### **Sponsor**

Accredited Standards Committee X12

### **Purpose**

X12N Insurance Subcommittee has a number of standards that relate to aspects of insurance and insurance-related business processes including, but not limited to, property, casualty, health care, life, annuity, reinsurance, pensions, and reporting to regulatory agencies.

### **Version**

Unknown

### **Year Current Version Was Adopted**

Unknown

### **Age of Standard**

1990

### **Federal Involvement/Endorsement**

Unknown

### **Who Uses**

Healthcare providers and payors

### **Mandatory/Voluntary (and Authorization)**

HIPAA requires use of this standard when submitting claims and performing other specified financial and administrative transactions electronically, including specification of ICD-9-CM.

### **Estimate of Adoption**

Unknown



## Standards Development Process

X12N Subcommittee membership is open to any ASC X12 member in good standing. Organizational membership in the subcommittee is vested in the organization, not the individual. ASC X12 is the American National Standards Institute Standards Development Organization that oversees ASC X12N. ASC X12N is the “Insurance” subcommittee of ASC X12. ASC X12 provides a neutral environment and an appropriate structure to foster data standards development and implementation. ASC x12 is an ANSI organization and therefore follows ANSI processes for standards development participation. Hundreds of organizations representing the Fortune 500, small and mid-sized companies, industry associations, and government agencies participate in ASC X12.

## Type of Content

Major healthcare-related transaction standards apply to providers and payers.

- 270/271 – eligibility and enrollment
- 837 – claims
- 835/820 – enrollment, premium payment
- 276/277 – claim status
- 275/CDA – patient information
- 278 – healthcare services review
- 274 – provider information
- 824 – insurance transaction acknowledgement

## Unit of Collection

Varies by transaction type

## Data Availability

Unknown

## Relationship to other Standards

Since 1997 X12 and Health Level 7 (HL7) have been working together to develop a national standard for healthcare claim attachments to meet the attachments requirement under HIPAA. ASC X12’s EDI-INT is the preferred secure transfer methodology for HIPAA and payments.

## Future Plans

Unknown

## Vendors Incorporating In Products

Yes





### **Key Documents and Reports**

X12 standards and guidelines may be purchased from the Data Interchange Standards Association at [www.disa.org](http://www.disa.org)

### **Web Site**

Accredited Standards Committee X12N Insurance Subcommittee Web site:

[http://www.x12.org/x12org/subcommittees/sc\\_home.cfm?strSC=N](http://www.x12.org/x12org/subcommittees/sc_home.cfm?strSC=N)

### **For More Information**

Margaret Weiker, Chair

X12N

EDS, an HP Company

E-mail: [margaret.weiker@eds.com](mailto:margaret.weiker@eds.com)

### **Reviewed**

No





# Certification Commission for Healthcare Information Technology (CCHIT)

## Sector

Health care

## Type of Standard

Certification Organization

## Sponsor

CCHIT

## Purpose

CCHIT is an independent 501(c)3 organization with a public mission to accelerate the adoption of robust, interoperable healthcare information technology throughout the United States by creating an efficient, credible, sustainable mechanism for the certification of healthcare IT products and health information exchanges.

## Version

CCHIT currently offers certification for vendors of:

- Ambulatory Electronic Health Records
- Inpatient Electronic Health Records
- Emergency Department Electronic Health Records
- Health Information Exchanges

## Year Current Version Was Adopted

- Ambulatory Electronic Health Records - 2008
- Inpatient Electronic Health Records – 2008
- Emergency Department Electronic Health Records – 2008
- Health Information Exchanges - 2008

## Age of Standard

- Ambulatory Electronic Health Records - 2006
- Inpatient Electronic Health Records – 2007
- Emergency Department Electronic Health Records - 2008
- Health Information Exchanges -2008



### **Federal Involvement/Endorsement**

In October 2005, CCHIT was awarded a 3-year contract by the U.S. Department of Health and Human Services to develop, create prototypes for, and evaluate the certification criteria and inspection process for electronic health records and health information exchanges. The HHS funding was transitional, designed to support certification development, testing, and assessment, after which CCHIT will transition to a self-sustaining model.

### **Who Uses**

Vendors, healthcare providers with internally developed systems

### **Mandatory/Voluntary (and Authorization)**

Voluntary

### **Estimate of Adoption**

A large number of products have been certified. A listing is available at: <http://www.cchit.org/index.asp>

### **Standards Development Process**

In executing the work under the HHS contract, CCHIT has expanded its inclusive governance process that engages multiple stakeholders to ensure an objective, open, and consensus-driven process and credible result. Stakeholders will include:

- Clinicians and provider organizations who purchase health IT products;
- Safety net providers who purchase or receive health IT products;
- Vendors who develop, market, install, and support health IT products;
- Payers or purchasers who are prepared to offer incentives for health IT adoption;
- Healthcare consumers;
- Quality organizations;
- Public health agencies;
- Clinical and health-services researchers;
- Standards development organizations;
- Federal agencies, and coordinating bodies representing various federal agencies as identified by the National Coordinator.

CCHIT has 12 Work Groups—Ambulatory EHR, Behavioral Health, Cardiovascular Medicine, Child Health, Electronic Prescribing, Emergency Department, Health Information Exchange, Interoperability, Inpatient EHR, Personal Health Records, Privacy and Compliance, and Security—as well as a special PHR Advisory Task Force.





## **Type of Content**

Certification for Ambulatory Electronic Health Records, Emergency Department Electronic Health Records, Health Information Exchanges, and Inpatient Electronic Health Records

## **Unit of Collection**

Patient

## **Data Availability**

Not applicable, as this is a certification process

## **Relationship to other Standards**

CCHIT collaborates with National eHealth Collaborative (NeHC), and those organizations awarded HHS contracts for standards harmonization (HITSP), prototype development for a nationwide health information network (NHIN) architecture, and assessment of privacy and security laws and practices. CCHIT will also consider how existing certification processes work and collaborate with the Department of Commerce's National Institute of Standard and Technology (NIST).

## **Future Plans**

HIE certification program modules are to be released over 6 months, the last delivered in April 2009. Personal Health Record and standalone Electronic Prescribing certification will be launched in July 2009. The Commission's proposed roadmap includes development of several new certification programs for launch in 2010. Two areas already named in previous years, Behavioral Health and Long-Term Care, will be developed as planned. In addition, four new program areas are proposed, all of which are optional add-on certifications for Ambulatory EHRs: Clinical Research, Dermatology, Advanced Interoperability, and Advanced Quality. The roadmap identifies additional areas for future consideration, even though programs for them may not be ready for launch in 2010. These include Eye Care, Oncology, Obstetrics/Gynecology, Advanced Security, and Advanced Clinical Decision Support.

## **Vendors Incorporating In Products**

Yes. A large number of products have been certified. A listing is available at: <http://www.cchit.org/index.asp>

## **Key Documents and Reports**

Case studies of CCHIT Certified EHRs in practice: <http://www.cchit.org/about/casestudies/index.asp>

## **Web Site**

Certification Commission for Healthcare Information Technology: [www.cchit.org](http://www.cchit.org),  
<http://ehrdecisions.com>; <http://phrdecisions.com>





**For More Information**

Sue Reber, Marketing Director  
Certification Commission for Healthcare Information Technology  
200 S. Wacker Drive, Suite 3100  
Chicago, IL, 60606  
Telephone: (503) 288-5876  
Facsimile: (503) 287-4613  
E-mail: sreber@cchit.org

**Reviewed**

Yes





# Clinical Document Architecture (CDA)

**Sector**

Health care

**Type of Standard**

Overarching Framework

**Sponsor**

HL7/ANSI

**Purpose**

Clinical Document Architecture (CDA) is an HL7 standard that provides an exchange model for clinical documents (such as discharge summaries and progress notes) and is an important step toward implementation of EHRs. The CDA standards makes documents both machine-readable and human-readable to enable easy retrieval and readability for users, while at the same time managing the integrity and attestability of the specific collection of data contained in the document. CDA was known earlier as the Patient Record Architecture (PRA).

**Version**

Release 2.0

**Year Current Version was Adopted**

2005

**Age of Standard**

2000

**Federal Involvement/Endorsement**

Unknown

**Who Uses**

Healthcare providers

**Mandatory/Voluntary (and Authorization)**

Voluntary

**Estimate of Adoption**

Unknown



## **Standards Development Process**

As an ANSI standard, it follows ANSI requirements for decisionmaking.

## **Type of Content**

The encounter, the patient, and the involved providers. Patient Example sections include: History of Present Illness, Past Medical History, Medications, Allergies and Adverse Reactions, Family History, Social History, Physical Exam [Vital Signs, Skin, Lungs, Cardiac], Laboratories, In-office Procedure, Assessment, Plan, and so forth

## **Unit of Collection**

Patient

## **Data Availability**

Unknown

## **Relationship to other Standards**

A CDA instance must adhere to the conformance rules stated in the CDA Hierarchical Description. The CDA Hierarchical Description is derived from the CDA R-MIM, which in turn is derived from the HL7 Reference Information Model (RIM) and user-controlled terminology such as SNOMED CT, LOINC, CPT, ICD, and RxNorm. The HL7 RIM is the definitive source for class and attribute definitions.

The CCD combines the benefits of ASTM's CCR and the CDA specifications.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Yes

## **Key Documents and Reports**

Health Level Seven Releases Updated Clinical Document Architecture (CDA) Specification:

<http://xml.coverpages.org/ni2004-08-20-a.html>

Hierarchical description (data dictionary): <http://xml.coverpages.org/healthcare.html#cda>

## **Web Site**

HL7 Web site: <http://www.hl7.org>





**For More Information**

John Quinn, Chief Technology Officer  
Health Level Seven, Inc.  
3300 Washtenaw Avenue, Suite 227  
Ann Arbor, MI 48104  
Telephone: (216) 409-1330  
E-mail: [jquinn@HL7.org](mailto:jquinn@HL7.org)

**Reviewed**

No





## Clinical Reporting System (CRS)

### Sector

Health care

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Indian Health Service

### Purpose

The Resource and Patient Management System (RPMS) is an IHS-wide system designed to provide detailed and comprehensive clinical and administrative information to providers and managers at all levels of the Indian health system in order to allow them to better manage individual patients, local facilities, and regional and national programs. It has several components for reporting detailed information on patient characteristics, diagnoses, and specific services provided to those patients. RPMS is a decentralized automated information system of over 50 integrated software applications with separate, individual databases at local sites. RPMS software modules fall into three major categories: (1) administrative applications that perform patient registration, scheduling, billing, and linkage functions; (2) clinical applications that support various healthcare programs within IHS; and (3) infrastructure applications. It has the capability to produce special reports, by individual provider, clinic, and outpatient versus inpatient services, in addition to other output generated from patient-level records. Taken together, the RPMS components collect, store, and then display an extensive abstract of clinical and administrative information gathered during patient contacts.

One of the RPMS applications, the Clinical Reporting System (CRS) is designed for national reporting as well as local and regional tracking of clinical performance measures. CRS is intended to eliminate the need for manual chart audits for evaluating and reporting clinical measures for local performance improvement initiatives, for regional tracking, as well as for national agency reporting to Congress and the Office of Management and Budget (OMB) as required by the Government Performance and Results Act (GPRA). CRS is also used for annual reporting of Transparency clinical measures required by Executive Order 13410 for transparency in quality measurements.

CRS produces reports on demand from local RPMS databases for one or more of 59 clinical topics, comprised of over 350 individual performance measures. Reports compare the site's performance numbers in the current report year (user defined) to the previous year and to a user-defined baseline year. Users can also request patient



lists for each of the measures, displaying patients who do and do not meet the measure criteria. For example, the GPRA Forecast provides a list of all GPRA measures patients will not meet as of their next scheduled appointment. The list enables providers to perform needed screenings and schedule needed tests at their appointment, thus, improving patient care and GPRA performance.

**Version**

Version 8.0 Patch 3

**Year Current Version Was Adopted**

2008

**Age of Standard**

2002

**Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Indian Health Service

**Who Uses**

Data are continually fed into the RPMS system as patients are served by IHS (for example, federal) and tribally operated and Urban Indian Health Program facilities that use RPMS. At sites where data entry into RPMS is performed by clerks from paper encounter forms that providers complete, there can be delays in this data entry that range from days to months. However, this is becoming less of an issue since IHS is working toward implementation of the electronic health record (EHR) at all IHS facilities.

Quality Improvement staff, Compliance Officers, GPRA Coordinators, clinical staff such as physicians, nurses, nurse practitioners, and other providers and staff involved with clinical quality improvement initiatives can use CRS to:

- Identify potential data issues in their RPMS (that is, missing or incorrect data)
- Monitor their site's performance against past national performance and upcoming agency goals
- Identify specific areas where clinical business process or other changes should be made to improve performance
- Quickly measure impact of process changes on performance measures

**Mandatory/Voluntary (and Authorization)**

Usage of the Clinical Reporting System for annual GPRA and Transparency reporting is mandated by the IHS Director for all IHS (for example, federal) facilities. Tribally operated facilities that have opted to report for GPRA and/or Transparency must use CRS to report. Urban Indian Health Program facilities are required





to report for GPRA but are not required to use CRS to report. Urban facilities that have opted to report for Transparency must use CRS to report. Usage of CRS for reporting of other clinical measures is voluntary.

IHS provides technical support for CRS users.

### **Estimate of Adoption**

CRS was distributed nationally to IHS, tribal, and urban facilities in 2008; 188 IHS and tribally operated facilities and 9 Urban Indian Health Program facilities used CRS to report for GPRA.

### **Standards Development Process**

IHS adheres to the standard software development life cycle for development of each CRS version. IHS extensively tests and evaluates each version before it is distributed nationally to IHS, tribal, and urban facilities, as described below.

- Changes to performance measure definitions are vetted by subject matter experts and performance measure field leads: 3–4 weeks
- Testing of software functionality and performance measure definitions by the lead developer prior to software being delivered to analyst staff: 3–4 weeks
- Testing of software functionality and performance measure definitions by analysts and federal lead with the lead developer: 2–4 months, depending on the level of changes
- Testing of software installation and conformance with programming standards by Software Quality Assurance (SQA): 2–3 weeks
- Testing of software functionality and performance measure definitions by beta test sites: 3–4 weeks and normally involves 3–5 beta test sites
- Final review and software release by SQA: 1 week

### **Type of Content**

Patient demographic and healthcare encounter data

### **Unit of Collection**

Individual

### **Data Availability**

The data are not available to those outside the agency in raw form, but users can request special data analyses.

### **Relationship to other Standards**

Several of the IHS quality measures are based on NCQA's HEDIS Effectiveness of Care measures; however, some have been revised to accommodate the needs of, and coding practices within, IHS.





## **Future Plans**

CRS is updated at least annually to reflect changes in clinical guidelines for existing measures as well as adding new measures to reflect new healthcare priorities. CRS Version 9.0 will include updated performance measure definitions and an expanded report for Transparency reporting. It is estimated CRS 9.0 will be released on June 30, 2009.

## **Vendors Incorporating In Products**

None

## **Key Documents and Reports**

- Software and documentation  
<http://www.ihs.gov/Cio/RPMS/index.cfm?module=home&option=software>
- CRS 8.0 Patch 2 Selected Measures (Local) Report Performance Measure List and Definitions  
[http://www.ihs.gov/cio/crs/documents/CRS\\_2008\\_v80Patch2\\_%20Selected%20Measures\\_Report\\_PerformanceMeasuresDefinitions\\_and\\_Logic-081508.pdf](http://www.ihs.gov/cio/crs/documents/CRS_2008_v80Patch2_%20Selected%20Measures_Report_PerformanceMeasuresDefinitions_and_Logic-081508.pdf)
- CRS 8.0 Patch 2 National GPRA Report Performance Measure List and Definitions  
[http://www.ihs.gov/cio/crs/documents/CRS\\_2008\\_National\\_GPRA\\_Report\\_Performance\\_Measure\\_List\\_and\\_Definitions-082108.pdf](http://www.ihs.gov/cio/crs/documents/CRS_2008_National_GPRA_Report_Performance_Measure_List_and_Definitions-082108.pdf)
- CRS 8.0 Patch 2 Executive Order (EO) Quality Transparency Measures Report Performance Measure List and Definitions  
[http://www.ihs.gov/cio/crs/documents/CRS\\_2008\\_v80Patch2\\_%20EO\\_Report\\_PerformanceMeasuresDefinitions\\_and\\_Logic-081508.pdf](http://www.ihs.gov/cio/crs/documents/CRS_2008_v80Patch2_%20EO_Report_PerformanceMeasuresDefinitions_and_Logic-081508.pdf)

## **Web Site**

U.S. Department of Health and Human Services, Indian Health Service CRS Web site:

<http://www.ihs.gov/cio/crs>

## **For More Information**

Stephanie Klepacki

CRS Federal Lead, IT Specialist (Policy and Planning)

IHS Office of Information Technology

5300 Homestead Road NE

Albuquerque, NM 87110

Telephone/Facsimile: (505) 821-4480

E-mail: [Stephanie.Klepacki@ihs.gov](mailto:Stephanie.Klepacki@ihs.gov)

## **Reviewed**

Yes





## Consolidated Health Informatics (CHI)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

The Consolidated Health Informatics (CHI) initiative is one of the Office of Management and Budget's (OMB) eGov initiatives

### Purpose

Consolidated Health Informatics (CHI) is a collaborative effort to adopt health information interoperability standards, particularly health vocabulary and messaging standards, for implementation in federal government systems. Ultimately CHI will establish a portfolio of existing clinical vocabularies and messaging standards enabling federal agencies to build interoperable federal health data systems.

### Version

CHI has adopted 20 uniform standards for electronic exchange of clinical information to be used across the federal health enterprise.

### Year Current Version Was Adopted

2004 – first phase of identifying uniform standards completed

### Age of Standard

On March 21, 2003, the Departments of Health and Human Services, Defense, and Veterans Affairs announced the first set of uniform standards for the electronic exchange of clinical health information to be adopted across the federal government. On May 6, 2004, the Departments of Health and Human Services, Defense, and Veterans Affairs announced the adoption of 15 additional standards agreed to by the CHI initiative to allow for electronic exchange of clinical information across the federal government. The 15 new standards build on the existing set of 5 standards adopted by HHS in March 2003. The new standards agreed to by federal agencies will be used as agencies develop and implement new information technology systems. During 2006, the Departments of Health and Human Services, Defense, and Veterans Affairs announced the adoption of three additional standards agreed to by the CHI initiative to allow for electronic exchange of clinical information across the federal government. The three new standards build on the existing set of standards adopted by HHS in 2003 and 2004. The new standards agreed to by federal agencies will be used as agencies develop and implement new information technology systems.



## **Federal Involvement/Endorsement**

There are approximately 20 federal agencies involved in this initiative. Outreach to the private sector is via NCVHS. CHI is an integral element of the Federal Health Architecture (FHA) Program that is in the Office of the National Coordinator for Health Information Technology.

## **Who Uses**

Federal agencies

## **Mandatory/Voluntary (and Authorization)**

Through the CHI governance process, all federal agencies will incorporate the adopted standards into their individual agency health data enterprise architecture used to build all new systems or modify existing ones.

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

There is a Consolidated Health Informatics Work Group that leads the work and is one of the five established FHA Work Groups.

## **Type of Content**

The standards all federal agencies will adopt are:

- Health Level 7 (HL7) messaging standards to ensure that each federal agency can share information that will improve coordinated care for patients such as entries of orders, scheduling appointments and tests, and better coordination of the admittance, discharge, and transfer of patients.
- National Council on Prescription Drug Programs (NCDPC) standards for ordering drugs from retail pharmacies to standardize information between health care providers and the pharmacies. These standards already have been adopted under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, and ensure that parts of the three federal departments that are not covered by HIPAA will also use the same standards.
- The Institute of Electrical and Electronics Engineers 1073 (IEEE1073) series of standards that allow for healthcare providers to plug medical devices into information and computer systems that allow healthcare providers to monitor information from an ICU or through telehealth services on Indian reservations and in other circumstances.
- Digital Imaging Communications in Medicine (DICOM) standards that enable images and





associated diagnostic information to be retrieved and transferred from various manufacturers' devices as well as medical staff workstations.

- Laboratory Logical Observation Identifier name Codes (LOINC) to standardize the electronic exchange of clinical laboratory results.
- Health Level 7 (HL7) vocabulary standards for demographic information, units of measure, immunizations, and clinical encounters, and HL7's Clinical Document Architecture standard for text-based reports. (Five standards)
- The College of American Pathologists Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) for laboratory result contents, non-laboratory interventions and procedures, anatomy, diagnosis and problems, and nursing. HHS is making SNOMED-CT available for use in the United States at no charge to users. (Five standards)
- Laboratory Logical Observation Identifier Name Codes (LOINC) to standardize the electronic exchange of laboratory test orders and drug label section headers. (One standard)
- The Health Insurance Portability and Accountability Act (HIPAA) transactions and code sets for electronic exchange of health-related information to perform billing or administrative functions. These are the same standards now required under HIPAA for health plans, healthcare clearinghouses, and those healthcare providers who engage in certain electronic transactions. (One standard)
- A set of federal terminologies related to medications, including the Food and Drug Administration's names and codes for ingredients, manufactured dosage forms, drug products, and medication packages; the National Library of Medicine's RxNORM for describing clinical drugs; and the Veterans Administration's National Drug File Reference Terminology (NDF-RT) for specific drug classifications. (One standard)
- The Human Gene Nomenclature (HUGN) for exchanging information regarding the role of genes in biomedical research in the federal health sector. (One standard)
- The Environmental Protection Agency's Substance Registry System for non-medicinal chemicals of importance to health care. (One standard)
- Digital Imaging Communications in Medicine (DICOM) standards to enable the exchange of multimedia information.
- Health Level 7 (HL7), SNOMED, the FDA SRS, and EPA SRS UNII Codes and RXNORM for the exchange of allergy information.
- Health Level 7 (HL7), International Classification of Functioning and Disability (ICF) and related CHI endorsed vocabularies for the exchange of Clinical Assessments and Disability and Functional Status.

## Unit of Collection

Varies





## Data Availability

Unknown

## Relationship to other Standards

Identified standards include:

- Health Level 7 (HL7) messaging standards to ensure that each federal agency can share information that will improve coordinated care for patients, such as entries of orders, scheduling appointments and tests, and better coordination of the admittance, discharge, and transfer of patients.
- National Council on Prescription Drug Programs (NCDPC) standards for ordering drugs from retail pharmacies to standardize information between healthcare providers and the pharmacies. These standards already have been adopted under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, and ensure that parts of the three federal departments that are not covered by HIPAA will also use the same standards.
- The Institute of Electrical and Electronics Engineers 1073 (IEEE1073) series of standards that allow for healthcare providers to plug medical devices into information and computer systems that allow healthcare providers to monitor information from an ICU or through telehealth services on Indian reservations and in other circumstances.
- Digital Imaging Communications in Medicine (DICOM) standards that enable images and associated diagnostic information to be retrieved and transferred from various manufacturers' devices as well as medical staff workstations.
- Laboratory Logical Observation Identifier name Codes (LOINC) to standardize the electronic exchange of clinical laboratory results.
- Health Level 7 (HL7) vocabulary standards for demographic information, units of measure, immunizations, and clinical encounters, and HL7's Clinical Document Architecture standard for text-based reports. (Five standards)
- The College of American Pathologists Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) for laboratory result contents, non-laboratory interventions and procedures, anatomy, diagnosis and problems, and nursing. HHS is making SNOMED-CT available for use in the United States at no charge to users. (Five standards)
- Laboratory Logical Observation Identifier Name Codes (LOINC) to standardize the electronic exchange of laboratory test orders and drug label section headers. (One standard)
- The Health Insurance Portability and Accountability Act (HIPAA) transactions and code sets for electronic exchange of health-related information to perform billing or administrative functions. These are the same standards now required under HIPAA for health plans, healthcare clearinghouses, and those healthcare providers who engage in certain electronic transactions. (One standard)





- A set of federal terminologies related to medications, including the Food and Drug Administration's names and codes for ingredients, manufactured dosage forms, drug products and medication packages; the National Library of Medicine's RxNORM for describing clinical drugs; and the Veterans Administration's National Drug File Reference Terminology (NDF-RT) for specific drug classifications. (One standard)
- The Human Gene Nomenclature (HUGN) for exchanging information regarding the role of genes in biomedical research in the federal health sector. (One standard)
- The Environmental Protection Agency's Substance Registry System for non-medicinal chemicals of importance to health care. (One standard)
- Digital Imaging Communications in Medicine (DICOM) standards to enable the exchange of multimedia information.
- Health Level 7 (HL7), SNOMED, the FDA SRS, and EPA SRS UNII Codes and RXNORM for the exchange of allergy information.
- Health Level 7 (HL7), International Classification of Functioning and Disability (ICF) and related CHI endorsed vocabularies for the exchange of Clinical Assessments and Disability and Functional Status.

CHI standards works in conjunction with the Health Insurance Portability and Accountability Act (HIPAA) transaction records and code sets and HIPAA security and privacy provisions. CHI plans to integrate with the HITSP process.

### **Future Plans**

CHI is focusing on

- Implementation of adopted standards,
- Maintenance of adopted standards
- Identification and adoption of new standards
- Integration into the HITSP process

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Variety of documents are available at: [www.hhs.gov/healthit/chi.html](http://www.hhs.gov/healthit/chi.html)

### **Web Site**

U.S. Health and Human Services, Office of the National Coordinator for Health Information Technology, Presidential Initiatives: [www.hhs.gov/healthit/chi.html](http://www.hhs.gov/healthit/chi.html)





**For More Information**

Vish Sankaran, Acting Program Manager

Federal Health Architecture

Office of the National Coordinator for Health Information Technology

U.S. Department of Health and Human Services

Telephone: (202) 205-2761

E-mail: [Vish.Sankaran@hhs.gov](mailto:Vish.Sankaran@hhs.gov)

**Reviewed**

No





## Continuity of Care Document (CCD)

### Sector

Health care

### Type of Standard

Data Interoperability Standard

### Sponsor

HL7/ANSI – and is a collaborative effort between ASTM and HL7

### Purpose

The Continuity of Care Document (CCD) combines the benefits of, and is an attempt to harmonize, ASTM's Continuity of Care Record (CCR) and the HL7 Clinical Document Architecture (CDA) specifications. CCD is an ANSI electronic document exchange standard for sharing patient summary information among providers and within personal health records. It summarizes the most commonly needed pertinent information about current and past health status in a form that can be shared by all computer applications, from Web browsers to electronic medical records. CCD attempts to capture a patient's health summary. CCD adds content to the CDA structure by describing various document sections such as patient demographics, insurance information, diagnosis and problem list, medications, allergies, and care plan that collectively can represent a "snapshot" of a patient's health data.

### Version

1.0

### Year Current Version was Adopted

2007

### Age of Standard

2007

### Federal Involvement/Endorsement

Healthcare Information Technology Standards Panel (HITSP) has named the CCD as the standard to satisfy the Consumer Empowerment use case for the content of a summary record of patient information.

### Who Uses

Healthcare providers





## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

HL7 is an ANSI standards development organization and therefore follows ANSI standards for standards development.

## **Type of Content**

Administrative (for example, registration, demographics, insurance, and so forth) and clinical (problem list, medication list, allergies, test results, and so forth) information

## **Unit of Collection**

Patient

## **Data Availability**

Unknown

## **Relationship to other Standards**

The CCD combines the benefits of ASTM's CCR and the HL7 Clinical Document Architecture (CDA) specifications.

CDA and CCD are derived from the HL7 Reference Information Model (RIM) and user-controlled terminology such as SNOMED CT, LOINC, CPT, ICD, and RxNorm.

HL7 has negotiated with CMS to use the CCD in place of the CDA for the HIPAA Claims Attachment Rule.

CCD and CCR are often seen as competing standards. An overview of similarities and differences is available at: [http://www.centerforhit.org/PreBuilt/chit\\_ccrhl7.pdf](http://www.centerforhit.org/PreBuilt/chit_ccrhl7.pdf)

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Yes





### **Key Documents and Reports**

Quick Start Guide developed by the EHR Vendors Association to support CCD implementers:

[http://www.ehrva.org/ASP/CCD\\_QSG\\_20071112.asp](http://www.ehrva.org/ASP/CCD_QSG_20071112.asp)

### **Web Site**

HL7 Web site: <http://www.hl7.org>

### **For More Information**

John Quinn, Chief Technology Officer

Health Level Seven, Inc.

3300 Washtenaw Avenue, Suite 227

Ann Arbor, MI 48104

Telephone: (216) 409-1330

E-mail: [jquinn@HL7.org](mailto:jquinn@HL7.org)

### **Reviewed**

No





## Continuity of Care Record (CCR)

### Sector

Health care

### Type of Standard

Data Interoperability Standard

### Sponsor

Joint standard developed by: American Society for Testing and Materials (ASTM) international E31 Committee on Health Informatics, Massachusetts Medical Society (MMS), Healthcare Information and Management Systems Society (HIMSS), American Academy of Family Physicians (AAFP)

### Purpose

The Continuity of Care Record (CCR) is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's health care, covering one or more healthcare encounters. It provides a means for one healthcare practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. The primary use case for the CCR is to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient. To ensure interchangeability of electronic CCRs, this specification specifies XML coding that is required when the CCR is created in a structured electronic format.

### Version

Version 1.0

### Year Current Version Was Adopted

2005

### Age of Standard

2005

### Federal Involvement/Endorsement

Unknown

### Who Uses

Healthcare providers



## **Mandatory/Voluntary (and Authorization)**

Voluntary

### **Estimate of Adoption**

Widely used in physician's offices and in other exchange efforts, such as Google Health, clinical messaging demonstrations, health information exchanges, and personal health records on cell telephones and patient portals.

### **Standards Development Process**

ASTM International, originally known as the American Society for Testing and Materials, is the standards development organization (SDO) under whose auspices the CCR's technical workgroup, Healthcare Informatics E31.25 and its members have operated and been convened. ASTM International is one of the world's largest and oldest voluntary and accredited standards development organizations, with headquarters located outside Philadelphia, PA. In addition to developing healthcare IT standards, ASTM International develops and manages standards in over 150 industries, including aviation, petroleum, and fiber optics.

### **Type of Content**

Patient health status (for example, problems, medications, allergies) and basic information about insurance, advance directives, care documentation, and the patient's care plan

### **Unit of Collection**

Patient

### **Data Availability**

For exchange between providers

### **Relationship to other Standards**

CCR is a defined set of core data, specified in XML, that can be prepared, transmitted, and viewed in an HL7 CDA-compliant document. CCD and CCR are often seen as competing standards. An overview of similarities and differences is available at: [http://www.centerforhit.org/PreBuilt/chit\\_ccrhl7.pdf](http://www.centerforhit.org/PreBuilt/chit_ccrhl7.pdf)

### **Future Plans**

The ASTM Committee has maintained a list of enhancements that will form the basis for Version 2.0. When the balloting process will be initiated to begin formal development of 2.0 is unknown at this time.

### **Vendors Incorporating In Products**

Yes. Many EHR, PHR, and other health-IT vendors are working toward the ASTM Continuity of Care Record (CCR) Standard (E2369-05). The table below lists Partners for Patients companies and companies that are





part of the CCR Acceleration Task Force, and their EHR products. Companies provide the Center for Health Information Technology with estimated delivery times for their CCR-compliant products. For a listing of vendors maintained by AAFP's Center for Health Information Technology: <http://www.centerforhit.org/x2022.xml>

### **Key Documents and Reports**

ASTM E2369-05 Standard Specification for Continuity of Care Record (CCR), with (XML Schema) Adjunct E2369, standard and licenses may be purchased at: <http://www.astm.org/Standards/E2369.htm>

### **Web Site**

ASTM continuity of Care Record Web site:

<http://www.astm.org/Standards/E2369.htm> and [www.ccrstandard.com](http://www.ccrstandard.com)

### **For More Information**

E31 ASTM Committee Contact

Daniel Smith, Staff Manager

Committee E31 on Healthcare Informatics

Telephone: (610) 832-9727

E-mail: [dsmith@astm.org](mailto:dsmith@astm.org)

CCR Technical Contact

Steven Waldren, MD

AAFP- Director, Center for Health IT

ASTM E31 Vice Chairman

E-mail: [swaldren@aafp.org](mailto:swaldren@aafp.org)

### **Reviewed**

Yes





## Electronic Healthcare Network Accreditation Commission (EHNAC)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

EHNAC

### Purpose

The Electronic Healthcare Network Accreditation Commission (EHNAC) is a federally recognized standards development organization and nonprofit accrediting body designed to improve transactional quality, operational efficiency, and data security in health care. Its mission is to promote standards-based accreditation within the healthcare data exchange industry. EHNAC, an independent, 501(c)(6) not-for-profit accrediting agency, grew out of the 1993 Workgroup for Electronic Data Interchange (WEDI), sponsored by the Network Architecture and Accreditation Technical Advisory Group.

### Version

The five healthcare-related accreditations EHNAC offers are:

- Healthcare Network Accreditation Program (HNAP) – Electronic Health Network (EHN) accreditation recognizes excellence in health data processing and transactions and indicates compliance with industry-established standards and HIPAA regulations.
- e-Prescribing Accreditation Program (ePAP) accreditation ensures e-prescribing quality business performance through compliance with all necessary and relevant industry-established guidelines, standards, and criteria.
- Financial Services Accreditation Program (FSAP) – Electronic Health Network (EHN) demonstrates that a financial services organization meets a high standard of quality in handling protected health information as well as ensuring that it follows industry-established criteria for processing payments and other financial transactions.
- Financial Services Accreditation Program (FSAP)– Lockbox differs from the other EHNAC accreditation programs in that certain performance metrics are modified or not included since a lockbox operation does not receive standards-based transactions. Also, specific document handling and delivery criteria are unique to this program.





- HNAP Plus Select SAS 70(©) Criteria (HNAP 70) [SAS 70(©) is a proprietary term owned by the American Institute of Certified Public Accountants (AICPA)] ensures that an organization's general IT controls are more comprehensive to assist in the preparation of SAS 70(©)1 or Sarbanes-Oxley audits.

### **Year Current Version was Adopted**

- Healthcare Network Accreditation Program (HNAP) – Electronic Health Network (EHN) - 2009
- e-Prescribing Accreditation Program (ePAP) - 2009
- Financial Services Accreditation Program (FSAP) – Electronic Health Network (EHN) - 2009
- Financial Services Accreditation Program (FSAP) – Lockbox - 2009
- Healthcare Network Accreditation Program (HNAP) - 70- 2009

### **Age of Standard**

Fifteen years with each standard reviewed and revised annually. Current versions of the standards were released January 1, 2009.

### **Federal Involvement/Endorsement**

Unknown

### **Who Uses**

Health care payers, providers, financial services organizations, and network exchanges

### **Mandatory/Voluntary (and Authorization)**

Mandatory for payers that utilize electronic healthcare networks (EHNs) in the states of Maryland and New Jersey. Voluntary for all other states.

### **Estimate of Adoption**

Approximately 60–75 percent of known healthcare EHNs are EHNAC accredited. The ePAP adoption percentage is unknown at this time.

### **Standards Development Process**

The Development Process includes promulgated proposed standards through Web site and notifications, public comment periods, and voting by the Commissioners. EHNAC follows the American National Standards Institute (ANSI X12N) standards development process.





## Type of Content

- Healthcare Network Accreditation Program (HNAP) - is the “stamp of approval” from industry peers recognizing excellence in health data processing and transactions, HNAP is the choice for organizations that manage and transfer protected health information. HNAP accreditation indicates that your organization exceeds industry-established standards and complies with HIPAA regulations in areas such as privacy measures; systems availability; and security infrastructure. To further accommodate an expanding field, EHNAC offers several additional subcategories of HNAP accreditation with criteria more specific to the needs of payer-owned networks, third-party administrators, medical billers, transcriptionists, and more.
- e-Prescribing Accreditation Program (ePAP) - assesses your electronic prescribing and Facsimile-based prescribing transactions for transaction timeliness, accommodation of industry-standard data formats, and security measures. ePAP gives your existing and prospective customers confidence that you meet all necessary standards for disciplined, quality business performance.
- Financial Services Accreditation Program (FSAP) - For banks, financial services firms, and other vendors seeking to differentiate themselves by demonstrating they adhere to a higher standard of quality, FSAP is the perfect solution. FSAP ensures that your organization follows HIPAA security and privacy rules and meets a range of criteria applicable specifically to financial electronic health networks. FSAP accreditation assures your customers that their business partner follows industry-established standards for processing payment and other transactions involving protected health information. EHNAC evaluates each FSAP applicant against 16 financial criteria and 3 criteria that apply exclusively to financial and banking electronic health networks. EHNAC offers several categories of FSAP accreditation to more closely match your situation: FSAP EHN and FSAP Lockbox.

## Unit of Collection

Self-Assessment and onsite review.

## Data Availability

Criteria is available on Web site [http://www.ehnac.org/ap\\_criteria.html](http://www.ehnac.org/ap_criteria.html)

## Relationship to other Standards

The accreditation criteria refer to numerous standards.

## Future Plans

EHNAC has begun development of a new accreditation program for health information exchange (HIE).

Designed for regional health information organizations (RHIOs), community health data/network partnerships



and other groups that promote data sharing across multiple, independent stakeholders, the HIE program will assess the privacy policies, security measures, technical performance, business practices, and organizational resources of participating entities. An EHNAC advisory group recently completed an HIE market scan white paper.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

All criteria is available on the Web site [http://www.ehnac.org/ap\\_criteria.html](http://www.ehnac.org/ap_criteria.html)

### **Web Site**

Electronic Healthcare Network Accreditation Commission (EHNAC) Web site:

<http://www.ehnac.org/index.html>

### **For More Information**

Debra Hopkinson, Operations Director

Electronic Healthcare Network Accreditation Commission (EHNAC)

25 Brookshire Lane

Farmington, CT 06032

Telephone: (860) 676-8595

Facsimile: (860) 760-6630

E-mail: [dhopkinson@ehnac.org](mailto:dhopkinson@ehnac.org)

### **Reviewed**

Yes





## Federal Health Architecture (FHA)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology

### Purpose

The Federal Health Architecture (FHA) was established as an eGov Line of Business in response to The President's Management Agenda calling for increased efficiency and effectiveness in government operations. The FHA is responsible for:

- Leveraging federal expertise in creating a federal framework that would be derived from a national health IT infrastructure.
- Supporting federal activities in the development and adoption of health IT standards.
- Ensuring that federal agencies can seamlessly exchange health data between and among themselves, with state, local, and tribal governments, and with private sector healthcare organizations.

### Version

Not applicable

### Year Current Version Was Adopted

Not applicable

### Age of Standard

In April 2004, President Bush issued Executive Order #13335 which established the Office of the National Coordinator for Health IT (ONC), through the Department of Health and Human Services, to coordinate health IT activities in the federal space and also to coordinate with the private sector.

### Federal Involvement/Endorsement

FHA is a partnership among federal agencies, the Office of the National Coordinator for Health IT (ONC), and the Office of Management Budget (OMB). The Department of Health and Human Services as the Managing



Partner along with the Department of Defense and the Department of Veterans Affairs as Lead Partners provide funding for the program. Additionally, approximately 20 agencies contribute time and expertise to participate in specific FHA activities. Agencies include Department of Homeland Security, Department of Agriculture, Environmental Protection Agency, National Aeronautics and Space Administration, Department of Housing and Urban Development, Department of Commerce, Department of Energy, Department of Transportation, Department of State, Social Security Administration, Department of Labor, Office of Personnel Management, Department of Justice, National Science Foundation, Department of Treasury, U.S. Agency for International Development, and Small Business Administration.

**Who Uses**

Federal agencies

**Mandatory/Voluntary (and Authorization)**

In April 2004, the President Bush issued Executive Order #13335 which established the Office of the National Coordinator for Health IT (ONC), through the Department of Health and Human Services, to coordinate health IT activities in the federal space and also to coordinate with the private sector.

**Estimate of Adoption**

Unknown

**Standards Development Process**

Unknown

**Type of Content**

Not applicable

**Unit of Collection**

Not applicable

**Data Availability**

Not applicable





## Relationship to other Standards

FHA participates in:

- American Health Information Community (AHIC)
- Health IT Standards Panel (HITSP)
- Certification Commission for Healthcare Information Technology (CCHIT)
- National Committee on Vital and Health Statistics (NCVHS)
- Health IT Policy Council (HITPC)
- Department of Health and Human Services -HITPC
- Federal Health Architecture Response Teams

## Future Plans

FHA is actively involved in national health IT initiatives to ensure that the federal perspective is represented and coordinated in support of the health IT plan established by President Bush:

- The Community approved a recommendation for the development of a use case for an EHR to be used in emergency response situations. FHA was tasked by The
- Community to lead this effort with active input from leading organizations in the private and public sectors. The use will be developed by October 2006.
- HHS Secretary Leavitt has tasked FHA with assisting agencies in developing a plan to implement standards endorsed by the Health Information Technology Standards Panel (HITSP) and adopted by the Secretary of HHS.
- FHA is supporting OMB in surveying federal agencies to identify the current state of interoperability.
- FHA is coordinating federal input into the health IT standards harmonization and nationwide health information network (NHIN) processes. Activities include oversight and coordination of Interoperability Specifications Inspection Testing and providing testimony on NHIN functional requirements.

## Vendors Incorporating In Products

Unknown

## Key Documents and Reports

Federal Health Architecture: Frequently Asked Questions (PDF): <http://www.hhs.gov/fedhealtharch/FAQ.pdf>

## Web Site

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, Federal Health Architecture Web site: <http://www.hhs.gov/fedhealtharch>



**For More Information**

Vish Sankaran, Acting Program Manager

Federal Health Architecture

Office of the National Coordinator for Health Information Technology

U.S. Department of Health and Human Services

Telephone: (202) 205-2761

E-mail: [Vish.Sankaran@hhs.gov](mailto:Vish.Sankaran@hhs.gov)

**Reviewed**

No





## Health Information Technology Standards Panel (HITSP)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

HITSP/ANSI

### Purpose

The Healthcare Information Technology Standards Panel (HITSP) was charged with bringing U.S. standards developers and other stakeholders together to develop, prototype, and evaluate a harmonization process for achieving a widely accepted and useful set of health IT standards that will support interoperability among healthcare software applications. The mission of HITSP is to serve as a cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional, and national health information network for the United States.

### Version

- Electronic Health Records Laboratory Results Reporting (IS 01): This Interoperability Specification defines specific standards to support the interoperability between electronic health records and laboratory systems and secure access to laboratory results and interpretations in a patient-centric manner.
  - ♦ Version: 2.1 Recognized
  - ♦ Version: 3.0 Released (Panel Approved)
- Biosurveillance (IS 02): This Interoperability Specification defines specific standards that promote the exchange of biosurveillance information among healthcare providers and public health authorities.
  - ♦ Version: 2.1 Recognized
  - ♦ Version: 3.1 Released (Panel Approved)
- Consumer Empowerment (IS 03): This Interoperability Specification defines specific standards needed to enable the exchange of data between patients and their caregivers.
  - ♦ Version: 2.1 Recognized
  - ♦ Version: 3.1 Released (Panel Approved)
- Emergency Responder Electronic Health Record (ER-EHR) (IS 04): This Interoperability





Specification defines specific standards required to track and provide onsite emergency care professionals, medical examiner/fatality managers, and public health practitioners with needed information regarding care, treatment, or investigation of emergency incident victims.

- ♦ Version: 1.1 Accepted
- ♦ Version 1.2 Released (Panel Approved)
- Consumer Empowerment and Access to Clinical Information via Media (IS 05): This Interoperability Specification defines specific standards needed to assist patients in making decisions regarding care and healthy lifestyles (that is registration information, medication history, laboratory results, current and previous health conditions, allergies, summaries of healthcare encounters and diagnoses).
  - ♦ Version: 1.0 Accepted
  - ♦ Version 1.1 Released (Panel Approved)
- Quality (IS 06): This Interoperability Specification defines specific standards needed to benefit providers by providing a collection of data for inpatient and ambulatory care and to benefit clinicians by providing real-time or near-real-time feedback regarding quality indicators for specific patients.
  - ♦ Version: 1.0 Accepted
  - ♦ Version 1.1 Released (Panel Approval)
- Medication Management (IS 07): This Interoperability Specification defines specific standards to facilitate access to necessary medication and allergy information for consumers, clinicians, pharmacists, health insurance agencies, inpatient, and ambulatory care, and so forth.
  - ♦ Version: 1.1 Released (Panel Approved)
- Privacy and Security (TN 900): The HITSP Security and Privacy Technical Note addresses common data protection issues in a broad range of subject areas, including electronic delivery of laboratory results to a clinician, medication workflow for providers and patients, quality, and consumer empowerment.
  - ♦ Version: 1.1 Released (Panel Approved)

### **Year Current Version Was Adopted**

In 2006, the Interoperability Specifications were accepted by the Secretary of Health and Human Services for:

- Biosurveillance (IS 02)
- Consumer Empowerment (IS 03)
- Electronic Health Records Laboratory Results Reporting (IS 01)





In 2007, the Interoperability Specifications were accepted by the Secretary of Health and Human Services for:

- Consumer Empowerment and Access to Clinical Information via Media (IS 05)
- Emergency Responder Electronic Health Record (ER-EHR) (IS 04)
- Medication Management (IS 07)
- Privacy and Security (TN 900)
- Quality (IS 06)

### **Age of Standard**

HITSP was founded in 2005

### **Federal Involvement/Endorsement**

In the fall of 2005, the U.S. Department of Health and Human Services' Office of the National Coordinator for Health Information Technology (ONC) awarded a contract to the American National Standards Institute (ANSI), in cooperation with strategic partners HIMSS, Booz Allen Hamilton, and Advanced Technology Institute, to administer a standards harmonization initiative.

### **Who Uses**

Healthcare vendors and their clients

### **Mandatory/Voluntary (and Authorization)**

Harmonized standards are mandatory for any federal contract as published in Federal Register, Vol. 73, No. 15, Wed., January 23, 2008, and Executive Order "Promote Quality and Efficient Health Care in Federal Government Administered or Sponsored Healthcare Programs"

### **Estimate of Adoption**

Unknown

### **Standards Development Process**

The mission of the Healthcare Information Technology Standards Panel is to serve as a cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional, and national health information network for the United States.

HITSP is committed to an open and transparent mode of operation:

- membership and participation is open to all interested parties;
- work products are published for public review and comment before approval;
- and all meetings are open for membership participation



The steps in the harmonization process are:

- Each HITSP Interoperability Specification defines a set of “constructs” that:
  - ♦ specify how to integrate and constrain selected standards to meet the business needs of a Use Case; and
  - ♦ define a roadmap to use emerging standards and to harmonize overlapping standards when resolved.
- In essence, a HITSP IS represents a suite of documents that integrate and constrain existing standards to satisfy a Use Case
- IS Status = State in the acceptance process
  - ♦ Released Panel approved for submission to HHS
  - ♦ Accepted Secretary of HHS has accepted for a period of testing
  - ♦ Recognized Secretary of HHS has recognized the IS for immediate implementation
- Revisions and updates may mean that multiple versions of some Interoperability Specifications exist with differing status levels

## Type of Content

- Electronic Health Records Laboratory Results Reporting (IS 01): This Interoperability Specification defines specific standards to support the interoperability between electronic health records and laboratory systems and secure access to laboratory results and interpretations in a patient-centric manner.
- Biosurveillance (IS 02): This Interoperability Specification defines specific standards that promote the exchange of biosurveillance information among healthcare providers and public health authorities.
- Consumer Empowerment (IS 03): This Interoperability Specification defines specific standards needed to enable the exchange of data between patients and their caregivers.
- Emergency Responder Electronic Health Record (ER-EHR) (IS 04): This Interoperability Specification defines specific standards required to track and provide onsite emergency care professionals, medical examiner/fatality managers, and public health practitioners with needed information regarding care, treatment, or investigation of emergency incident victims.
- Consumer Empowerment and Access to Clinical Information via Media (IS 05): This Interoperability Specification defines specific standards needed to assist patients in making decisions regarding care and healthy lifestyles (that is, registration information, medication history, laboratory results, current and previous health conditions, allergies, summaries of healthcare encounters, and diagnoses).
- Quality (IS 06): This Interoperability Specification defines specific standards needed to benefit providers by providing a collection of data for inpatient and ambulatory care and to benefit





clinicians by providing real-time or near-real-time feedback regarding quality indicators for specific patients.

- Medication Management (IS 07): This Interoperability Specification defines specific standards to facilitate access to necessary medication and allergy information for consumers, clinicians, pharmacists, health insurance agencies, inpatient, and ambulatory care, and so forth.
- Privacy and Security (TN 900): The HITSP Security and Privacy Technical Note addresses common data protection issues in a broad range of subject areas, including electronic delivery of laboratory results to a clinician, medication workflow for providers and patients, quality, and consumer empowerment.

### **Unit of Collection**

Varies, but patient-based

### **Data Availability**

Unknown

### **Relationship to other Standards**

The Panel's work is driven by a series of priorities (for example, Use Cases) issued by the American Health Information Community (AHIC). HITSP produces recommendations and reports in Interoperability Specifications and related Constructs. These work products are intended to be equally applicable to the developing Nationwide Health Information Network for the United States (NHIN) and also to community and regional health information exchange networks.

Because of 42 CFR Part 2, many electronic health records currently support granular consent and "break the glass." However, opponents point out that most legacy EHR-s do not. Of course, without granular consent, "break the glass" is just business as usual and probably without an audit trail. The essential problem is who will pay for upgrading or replacing these legacy systems? SAMHSA wants HITSP to make granular consent a NHIN messaging standard. Legacy EHR-s may only support "role-based" access control (for example, only physicians can see detailed PHI) in the near future, but because privacy concerns in this country go well beyond behavioral health, a strong NHIN standard could eventually become a gold standard for all health care.

### **Future Plans**

Panels are developing the following specifications:

- Consultations and Transfers of Care (IS 09): The exchange of information between clinicians, particularly between requesting clinicians and consulting clinicians, to support consultations such as specialty services and second opinions.



- ♦ Version: 0.0.2
- Personalized Health care (IS 08): The exchange of genomic/genetic test information, family health history, and the use of analytical tools in the electronic health record (EHR) to support clinical decisionmaking.
  - ♦ Version: 0.0.2
- Immunizations and Response Management (IS 10): The ability to communicate a subset of relevant information about needs for medication and prophylaxis resources, about resource availability, about their administration, and about the status of treated and immunized populations.
  - ♦ Version: 0.0.2
- Public Health Case Reporting (IS 11): Leveraging electronic clinical information to address population health data requirements.
  - ♦ Version: 0.0.2
- Remote Monitoring (IS 13): The exchange of physiological and other measurements from remote monitoring devices in three candidate workflows: Measurement and Communication, Monitoring and Coordination, Clinical Management.
  - ♦ Version: 0.0.2
- Patient-Provider Secure Messaging (IS 12): The Patient-Provider Secure Messaging Interoperability Specification describes the information flows, processes, and system capabilities that are required for patients to interact with their healthcare clinicians remotely using common computer technologies readily available in homes and other settings.
  - ♦ Version: 0.0.2

## **Vendors Incorporating In Products**

Yes

## **Key Documents and Reports**

Program of Work Web site that maintains harmonization standards progress: <http://www.hitsp.org>

## **Web Site**

Healthcare Information Technology Standards Panel (HITSP) Web site: <http://www.hitsp.org>





### **For More Information**

Jessica Kant

Coordinator, Standards Harmonization

Healthcare Information and Management Systems Society

Telephone: (312) 915-9283

Facsimile: (312) 915-9511

E-mail: [jkant@himss.org](mailto:jkant@himss.org)

### **Reviewed**

No





## Health Level (HL7)

### Sector

Health care

### Type of Standard

Data Interoperability Suite of Standards

### Sponsor

HL7/ANSI

### Purpose

Health Level Seven (HL7) is an ANSI-accredited standards development organization that provides standards for interoperability that improve care delivery, optimize workflow, reduce ambiguity, and enhance knowledge transfer among all stakeholders, including healthcare providers, government agencies, the vendor community, fellow SDOs, and patients.

### Version

HL7 promulgates a variety of standards (some explain as separate standards within this catalog). Its major standards include:

- Arden Syntax for Medical Logic Systems Version 2.7 - addresses the sharing of computerized health knowledge bases among personnel, information systems, and institutions. The scope has been limited to those knowledge bases that can be represented as a set of discrete modules. Each module, referred to as a Medical Logic Module (MLM), contains sufficient knowledge to make a single decision.
- Clinical Context Object Workgroup (CCOW) Version 1.5 - is a standard for clinical context management. It applies to desktop applications, allowing clinical applications to share information at the point of care. CCOW unifies the applications in use so that each refers to the same patient. The CCOW standards specify technology-neutral architectures, component interfaces, and data definitions as well as an array of interoperable technology-specific mappings of these architectures, interfaces, and definitions. [www.ccow-info.com](http://www.ccow-info.com)
- Clinical Document Architecture (CDA) Version 2.0 - provides an exchange model for clinical documents (such as discharge summaries and progress notes) - and brings the healthcare industry closer to the realization of an electronic medical record.
- Continuity of Care Document (CCD) Version 1.0 - is an implementation guide based on the CDA document exchange standard and is used to share patient summary information among providers and within personal health records. It summarizes the most commonly needed pertinent





information about current and past health status in a form that can be shared by all computer applications, from Web browsers to electronic medical records.

- EHR System Functional Model Version 1.0 - is a reference list of functions that may be present in an EHR system. The function list is described from a user perspective
- with the intent to enable consistent expression of system functionality. Through the creation of functional profiles, this model enables a standardized description and common understanding of functions sought or available in a given setting (for example, intensive care, cardiology, office practice in one country, or primary care in another country). [www.hl7.org/ehr](http://www.hl7.org/ehr)
- Messaging Standards Version 3. - is a model-based standard for exchanging messages among information systems that implement healthcare applications.
- HL7 Version Standard: Transport Specification - Electronic Business Extensible Markup Language (ebXML) Version 1.0 - describes the ebXML message wrappers and transport architecture that may be used to securely exchange HL7 V3 content over a variety of lower level transports such as TCP, HTTP, and SMTP.
- HL7 Version 2.x, the messaging standard (Application Protocol for Electronic Data Exchange in Healthcare Environments) from HL7, is the most widely implemented standard for healthcare information in the world and seen as the “workhorse” of data exchange in health care.
- Reference Information Model (RIM) Version 1 - is a large model language and pictorial representation of the clinical data (domains) and identifies the life cycle of events that a Version 3 message or groups of related messages will carry.

### **Year Current Version was Adopted**

- Arden Syntax for Medical Logic Systems - 2008
- Clinical Context Object Workgroup (CCOW) - 2006
- Clinical Document Architecture (CDA) - 2004
- Continuity of Care Document (CCD) - 2007
- Electronic Business Extensible Markup Language (ebXML) - 2008
- EHR System Functional Model - 2007
- HL7 V2.6 Messaging Standard - 2007
- Reference Information Model (RIM) - 2003

### **Age of Standard**

- Arden Syntax for Medical Logic Systems - This standard was transferred from ASTM to HL7. HL7's first Arden documents were approved in 1999.
- Clinical Context Object Workgroup (CCOW) - 1999
- Clinical Document Architecture (CDA) - 2000





- Continuity of Care Document (CCD)
- Electronic Business Extensible Markup Language (ebXML) - 2008
- EHR System Functional Model - 2004
- HL7 Version 2 Messaging Standard - 1997 (first ANSI accredited version)
- Reference Information Model (RIM) - 2003

### **Federal Involvement/Endorsement**

Various HL7 standards have been incorporated into the HITSP standards harmonization process: [http://www.hl7.org/documentcenter/public/faq/HL7\\_Standard-HITSP\\_IS\\_V1090808.pdf](http://www.hl7.org/documentcenter/public/faq/HL7_Standard-HITSP_IS_V1090808.pdf) for the current list

HL7 has negotiated with CMS to use the CCD in place of the CDA for the HIPAA Claims Attachment Rule.

SAMHSA and members of the SAMHSA-funded Behavioral Health Standards Workgroup contribute to the NHII in three ways:

- Represent behavioral health within Health Level Seven (HL7), including development of the HL7 EHR Functional Model and the HL7 functional standard for consent-to-disclose personal health information (PHI)
- Development of a ‘certification profile’ for CCHIT certification of Electronic Behavioral Health Record systems (EBHR-s), based on the HL7 Functional Model

CHI has determined that the standards all federal agencies will adopt are:

- Health Level Seven (HL7) messaging standards to ensure that each federal agency can share information that will improve coordinated care for patients, such as entries of orders; scheduling appointments and tests; and better coordination of the admittance, discharge, and transfer of patients.
- Health Level Seven (HL7) vocabulary standards for demographic information, units of measure, immunizations, and clinical encounters, and HL7’s Clinical Document Architecture standard for text-based reports. (Five standards)
- Health Level Seven (HL7), SNOMED, the FDA SRS and EPA SRS UNII Codes, and RXNORM for the exchange of allergy information
- Health Level Seven (HL7), International Classification of Functioning and Disability (ICF), and related CHI endorsed vocabularies for the exchange of Clinical Assessments and Disability and Functional Status

### **Who Uses**

Healthcare organizations





### **Mandatory/Voluntary (and Authorization)**

Varies depending on standard

### **Estimate of Adoption**

Some of the standards are widely adopted; others less so. For example, it is the accepted messaging standard for communicating clinical data. It is supported by every major medical informatics system vendor in the United States.

### **Standards Development Process**

HL7 is an ANSI standards development organization and abides by ANSI guidelines for openness and transparency. HL7 also promotes ANSI-approved standards to the ISO level.

### **Type of Content**

Enables interoperability between healthcare information systems, such as electronic patient administration and management systems; laboratory information systems; dietary, pharmacy, and billing systems as well as EHR systems

### **Unit of Collection**

Varies based on standard

### **Data Availability**

Data is shared between users

### **Relationship to other Standards**

Since 1997 X12 and Health Level Seven (HL7) have been working together to develop a national standard for healthcare claim attachments to meet the attachments requirement under HIPAA. ASC X12's EDI-INT is the preferred secure transfer methodology for HIPAA and payments.

The Continuity of Care Document (CCD) combines the benefits of, and is an attempt to harmonize, ASTM's Continuity of Care Record (CCR) and the HL7 Clinical Document Architecture (CDA) specifications.

CDA and CCD are derived from the HL7 Reference Information Model (RIM) and user-controlled terminology such as SNOMED CT, LOINC, CPT, ICD, and RxNorm.

HL7 has negotiated with CMS to use the CCD in place of the CDA for the HIPAA Claims Attachment Rule.

### **Future Plans**

Unknown





### **Vendors Incorporating In Products**

Varies based on standard

### **Key Documents and Reports**

HL7 Standards information and downloads at: <http://www.hl7.org/Library/standards.cfm>

### **Web Site**

HL7 Web site: <http://www.hl7.org>

### **For More Information**

John Quinn, Chief Technology Officer

Health Level Seven, Inc.

3300 Washtenaw Avenue, Suite 227

Ann Arbor, MI 48104

Telephone: (216) 409-1330

E-mail: [jquinn@HL7.org](mailto:jquinn@HL7.org)

### **Reviewed**

Yes





# Integrating the Healthcare Enterprise (IHE)

## Sector

Health care

## Type of Standard

Standards Development Organization/Harmonization Effort

## Sponsor

IHE

## Purpose

Integrating the Healthcare Enterprise (IHE) is an initiative by healthcare professionals and industry to improve the way computer systems in health care share information. IHE promotes the coordinated use of established standards such as DICOM and HL7 to address specific clinical need in support of optimal patient care.

Systems developed in accordance with IHE communicate with one another better, are easier to implement, and enable care providers to use information more effectively. IHE Profiles organize and leverage the integration capabilities that can be achieved by coordinated implementation of communication standards. Profiles provide precise definitions of how standards can be implemented to meet specific clinical needs. IHE has trial or final profiles in the domains of:

- Anatomic Pathology
- Cardiology
- Eye Care
- IT Infrastructure
- Laboratory
- Patient Care Coordination
- Patient Care Devices
- Quality, Research, and Public Health
- Radiation Oncology
- Radiology

## Version

Unknown for each profile

## Year Current Version was Adopted

Unknown for each profile



### **Age of Standard**

Unknown for each profile

### **Federal Involvement/Endorsement**

Unknown for each profile

### **Who Uses**

Healthcare providers

### **Mandatory/Voluntary (and Authorization)**

Voluntary

### **Estimate of Adoption**

Unknown for each profile

### **Standards Development Process**

The work of IHE is managed by a coordinated set of committees sponsored by various national and international bodies.

IHE follows a defined, coordinated process for standards adoption. These steps repeat annually, promoting steady improvements in integration.

1. **Identify Interoperability Problems.** Clinicians and IT experts work to identify common interoperability problems with information access, clinical workflow, administration, and the underlying infrastructure.
2. **Specify Integration Profiles.** Experienced healthcare IT professionals identify relevant standards and define how to apply them to address the problems, documenting them in the form of IHE integration profiles.
3. **Test Systems at the Connectathon.** Vendors implement IHE integration profiles in their products and test their systems for interoperability at the annual IHE Connectathon. This allows them to assess the maturity of their implementation and resolve issues of interoperability in a supervised testing environment.
4. **Publish Integration Statements for use in RFPs.** Vendors publish IHE integration statements to document the IHE integration profiles their products support. Users can reference the IHE integration profiles in requests for proposals, greatly simplifying the systems acquisition process.



**Type of Content**

Varies by domain profile

**Unit of Collection**

Varies by domain profile

**Data Availability**

Unknown

**Relationship to other Standards**

The Public Health Data Standards Consortium has been invited by IHE to start a Public Health Domain at IHE. PHDSC and IHE are collaborating to enable interoperability across clinical and public health enterprises.

**Future Plans**

The Public Health Data Standards Consortium has been invited by IHE to start a Public Health Domain at IHE.

**Vendors Incorporating In Products**

Unknown

**Key Documents and Reports**

IHE Profiles for Users available at: <http://www.ihe.net/profiles/index.cfm>

**Web Site**

Integrating the Healthcare Enterprise Web site: <http://www.ihe.net>

**For More Information**

Didi Davis, Senior Director for IHE  
Healthcare Information and Management Systems Society  
230 East Ohio Street, Suite 500  
Chicago, IL 60611-3270  
Telephone: (865) 671-1624  
E-mail: [ddavis@himss.org](mailto:ddavis@himss.org)

**Reviewed**

No







## **Medicaid Analytic Extract (MAX) extracted from the Medicaid Statistical Information System (MSIS)**

### **Sector**

Health care

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### **Purpose**

The Medicaid Analytic Extract (MAX) files (formerly State Medicaid Research Files-SMRF) comprise data that have been extracted and restructured from the Medicaid Statistical Information System (MSIS) into which states report Medicaid expenditures through their own Medicaid Management Information Systems (MMIS). States submit their Medicaid data from their MMIS to the Medicaid Statistical Information System (MSIS). MSIS data are cleaned and restructured to become the MAX files. Researchers and policymakers use the MAX data. The MAX data are created to support research and policy analysis for Medicaid and the State Child Health Insurance Program (SCHIP).

### **Version**

The latest version of MAX is available for calendar year 2005. MSIS reporting standards are updated over time.

### **Year Current Version Was Adopted**

2009

### **Age of Standard**

MSIS reporting: 1987—voluntary effort started; 1999—production with all states

### **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### **Who Uses**

Access to the MAX data is controlled by the Privacy Act of 1974 because the data contain individual identifiers. Approved users include researchers and policy analysis in the federal government, state governments, academic institutions, and consulting firms.



## **Mandatory/Voluntary (and Authorization)**

### **Mandatory**

In 1987, a small number of states began voluntarily reporting data from their Medicaid claims processing systems into the Medical Statistical Information System (MSIS) in lieu of the hard-copy statistical 2082 tables. By 1998, the number of states voluntarily participating had grown to just under 40. The Balanced Budget Act (BBA) of 1997 mandated that all claims processed be submitted electronically through MSIS by 1999.

## **Estimate of Adoption**

All states report data

## **Standards Development Process**

CMS sets the reporting requirements, often with advice from advisory bodies and based on federal need. Decisions are promulgated through “Dear Medicaid Director” letters that notify states of new reporting requirements.

## **Type of Content**

MAX has two groups of files: the “Person Summary File” with eligibility information about each client/enrollee and summarized information on utilization and payments for Medicaid covered services. For each person enrolled in Medicaid, the Person Summary file contains information pertaining to why the person is eligible for Medicaid (for example, do they qualify under rules that apply because of age (65+) or disability, is their eligibility tied to receipt of cash assistance or other standards), which months during the year he/she was enrolled, whether he/she is also enrolled in Medicare or other health insurance, and basic personal characteristics (for example, age, race, gender).

The second group consists of four utilization and services files that provide details on each individual service: Inpatient (IP), Long-Term Care (LT), Other Services (OT), Prescription Drugs (RX).

## **Unit of Collection**

Client/enrollee and individual services

## **Data Availability**

MSIS data files are typically not released. MAX data files are available to researchers who have received approval from the CMS Privacy Board. Researchers must submit a proposal and comply with multiple criteria of the data use agreement. Note that only approved academic research projects and certain government agencies are entitled to a data use agreement to obtain MAX data. Data from CY 99–05 are available.





## **Relationship to other Standards**

MAX data are derived from MSIS.

## **Future Plans**

Every year, advisory bodies consider new data elements. There are also two large related initiatives that may expand MSIS data to provide additional data elements to assist CMS in the detection of fraud, abuse, and waste:

1. One Program Integrity (OnePI)
2. Medicaid Integrity Group

## **Vendors Incorporating In Products**

State MMIS vendors incorporate MSIS reporting requirements into their systems. CMS has a vendor that accepts and certifies MMIS data and restructures the data into MAX files.

## **Key Documents and Reports**

Introduction to Medicaid Analytic eXtract (MAX) Data and the Medicaid Analytic eXtract (MAX) Chartbook:

[http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07\\_MAXGeneralInformation.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp#TopOfPage)

MSIS Submission Format: <http://www.cms.hhs.gov/MSIS>

## **Web Site**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services Web site:

[http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07\\_MAXGeneralInformation.asp](http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp)

## **For More Information**

Dave Baugh, Senior Technical Advisor

CMS/ORDI,

Office of Research, Development, and Organization

Room C3-21-28

7500 Security Boulevard

Baltimore, MD 21244

Telephone: (410) 786-7716

Facsimile: (410) 786-5534

E-mail: [david.baugh@cms.hhs.gov](mailto:david.baugh@cms.hhs.gov)

Susan Radke, Health Insurance Specialist

CMS/ORDI

Office of Research, Development, and Organization





Room C3-21-28  
7500 Security Boulevard  
Baltimore MD 21244  
Telephone: (410) 786-4450  
Facsimile: (410) 786-5534  
E-mail: [susan.radke@cms.hhs.gov](mailto:susan.radke@cms.hhs.gov)

**Reviewed**

Yes





# Medicaid IT Architecture (MITA)

## Sector

Health care

## Type of Standard

Overarching Framework

## Sponsor

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Center for Medicaid and State Operations

## Purpose

Medicaid Information Technology Architecture (MITA) was created by CMS to support improved care quality through integrated and patient-centered information systems and program administration. MITA is establishing new national guidelines for technologies and business processes that will enable improved administration of the Medicaid program nationally, while allowing states flexibility to customize their business solutions locally. MITA is both an initiative and a framework. As an initiative, it is a plan to promote improvements in the Medicaid enterprise and the systems that support it through collaboration between CMS and the states. As a framework, MITA is a blueprint consisting of models, guidelines, and principles to be used by states as they implement business and technical enterprise solutions. It incorporates existing and evolving standards developed by national organizations, fosters shared leadership and partnership, and encourages use of nonproprietary systems and open-source code for data interoperability.

## Version

MITA Framework 2.0

## Year Current Version Was Adopted

2006

## Age of Standard

2004

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

## Who Uses

State Medicaid Agencies



## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

Over two thirds of all states are now engaged in some MITA activity, primarily performing MITA State Self Assessments to prepare for implementation.

## **Standards Development Process**

MITA governance will be controlled by the MITA Governance Board. The proposed structure for this body is a three-tiered organization, managed by CMS with both state and Vendor participation. The CMS MITA Web site has a section for the 2006 MMIS conference presentations. A presentation that explains the proposed MITA governance structure can be found there.

## **Type of Content**

Client

## **Unit of Collection**

Client

## **Data Availability**

Unknown

## **Relationship to other Standards**

MITA is aligned with the National Health Infrastructure Initiative (NHII). At level three of MITA maturity, the framework employs Service Oriented Architecture (SOA) and the exchange of business and technical services to support the execution of Medicaid business processes and uses existing standards, where possible, including the Health Level 7 (HL7) Reference Information Model (RIM), the Object Management Group (OMG), and the Organization for the Advancement of Structured Information Standards (OASIS).

SAMHSA is working with MITA developers to create a behavioral health version of MITA.

## **Future Plans**

MITA continues to mature as elements of the information and technical architectures are further developed. It is expected that state Medicaid systems will begin to implement MITA-aligned systems in 2011, with widespread adoption occurring through the following 2–3 years.





## **Vendors Incorporating In Products**

Vendors will use MITA to shape their product offerings to enable services to be leveraged and reused across states.

## **Key Documents and Reports**

MITA Framework: [http://www.cms.hhs.gov/MedicaidInfoTechArch/04\\_MITAFramework.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidInfoTechArch/04_MITAFramework.asp#TopOfPage)

MITA FAQ - Updated June, 2007: <http://www.cms.hhs.gov/MedicaidInfoTechArch/Downloads/mitaseries01.pdf>

## **Web Site**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services MITA Web site: <http://www.cms.hhs.gov/MedicaidInfoTechArch>

## **For More Information**

Robert Guenther, Technical Director  
Center for Medicaid and State Operations  
Finance, Systems, Budget Group  
Division of State Systems  
7500 Security Boulevard  
Mail Stop: S3-13-15  
Baltimore, MD 21244-1850  
Telephone: (410) 786-0618  
Facsimile: (410) 786-4005  
E-mail: [Robert.Guenther@cms.hhs.gov](mailto:Robert.Guenther@cms.hhs.gov)

## **Reviewed**

Yes







## Medicare Data Files

### Sector

Health care

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### Purpose

Centers for Medicare and Medicaid Services makes a number of Medicare Data Files available, based on information collected by Medicare for enrollment and payment of services.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

Unknown

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### Who Uses

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### Mandatory/Voluntary (and Authorization)

Mandatory

### Estimate of Adoption

CMS has created the reporting system and is the user.

### Standards Development Process

Unknown



## Type of Content

Of particular interest are two data files:

- Standard Analytical Files (SAFs) - contain information collected by Medicare to pay for healthcare services provided to a Medicare beneficiary. SAFs are available for each institutional (inpatient, outpatient, skilled nursing facility, hospice, or home health agency) and non-institutional (physician and durable medical equipment providers) claim type.
- Medicare Provider and Analysis Review File (MedPAR) Files - contain inpatient hospital and skilled nursing facility (SNF) final action stay records. Each MedPAR record represents a stay in an inpatient hospital or SNF.

## Unit of Collection

- Standard Analytical Files (SAFs) - the record unit of SAFs is the claim (some episodes of care may have more than one claim).
- Medicare Provider and Analysis Review Files (MedPAR) - an inpatient “stay” record summarizes all services rendered to a beneficiary from the time of admission to a facility through discharge. Each MedPAR record may represent one claim or multiple claims, depending on the length of a beneficiary’s stay and the amount of inpatient services used throughout the stay.

## Data Availability

CMS’s Identifiable Data files may be released by CMS under 1 of 12 Privacy Act Disclosure Exceptions. Identifiable data used for a health-related research, evaluation, or epidemiologic project fall under the Research Routine Use exception as presented in the Federal Register. The identifiable data requests are reviewed by a CMS Privacy Board. For more information: [http://www.resdac.umn.edu/Medicare/requesting\\_data.asp](http://www.resdac.umn.edu/Medicare/requesting_data.asp)

A variety of reports and data files are available at:

[http://www.resdac.umn.edu/medicare/data\\_file\\_descriptions.asp](http://www.resdac.umn.edu/medicare/data_file_descriptions.asp)

## Relationship to other Standards

Unknown

## Future Plans

Unknown





## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Data variable descriptions and download data dictionaries: <http://www.resdac.umn.edu/ddvh/index.asp>

## **Web Site**

Research and Data Assistance Center: [http://www.resdac.umn.edu/medicare/data\\_file\\_descriptions.asp](http://www.resdac.umn.edu/medicare/data_file_descriptions.asp)

## **For More Information**

Timothy P. Love, Director

Office of Research, Development and Information

Centers for Medicare and Medicaid Services

Room C3-20-11

7500 Security Boulevard

Baltimore, MD 21244

## **Reviewed**

No





## National Committee on Vital and Health Statistics (NCVHS)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort (NCVHS recommends health data standards for adoption but is not a standard-setting organization)

### Sponsor

U.S. Department of Health and Human Services

### Purpose

The National Committee on Vital and Health Statistics (NCVHS) was established more than 55 years ago by Congress as a public advisory body to the Department of Health and Human Services on health data, statistics, and national health information policy. With the 1996 passage of HIPAA, Congress selected the National Committee on Vital and Health Statistics (NCVHS) to advise the HHS secretary regarding what standards and versions to use for what functions, designated by HIPAA. NCVHS also deals with data related to population health, quality, and is the author of the original model for a national health information infrastructure (NHII). NCVHS has made recommendations related to the federal government's use of standards (the Consolidated Health Informatics standards) and, more recently, projects with the American Health Information Community and Office of the National Coordinator for Health Information Technology.

### Version

Not applicable

### Year Current Version Was Adopted

Not applicable

### Age of Standard

NCVHS was established in 1949

### Federal Involvement/Endorsement

NCVHS was established as a public advisory body to the Department of Health and Human Services. With the 1996 passage of HIPAA, Congress selected the NCVHS to advise the HHS secretary regarding what standards and versions to use for what functions, designated by HIPAA.

### Who Uses





Not applicable

**Mandatory/Voluntary (and Authorization)**

Not applicable

**Estimate of Adoption**

Not applicable

**Standards Development Process**

The Committee is composed of 18 individuals distinguished in the fields of health statistics, electronic interchange of healthcare information, privacy and security of electronic information, population-based public health, purchasing or financing healthcare services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Sixteen of the members are appointed by the Secretary of HHS for terms of 4 years each; with about four new members being appointed each year. Early each year, a Federal Register Notice announces the openings to be filled and invites nominations. An ad hoc selection committee is convened to review the letters of nomination and the curriculum vitae of those nominated. A slate of the most highly qualified people is reviewed by the HHS Data Council and recommendations are made to the Secretary for appointment. In the selection process, the Department gives close attention to equitable geographic distribution and to minority and female representation. Two additional members are selected by Congress. Current committees include:

- Ad Hoc Workgroup on the Secondary Uses of Health Data
- Executive Subcommittee
- Workgroup on National Health Information Infrastructure
- Subcommittee on Standards and Security
- Subcommittee on Privacy and Confidentiality
- Subcommittee on Populations
- Workgroup on Quality

**Type of Content**

Not applicable

**Unit of Collection**

Not applicable

**Data Availability**

Not applicable





### **Relationship to other Standards**

NCVHS was the author of the original model for a national health information infrastructure (NHII), an NHII work group. NCVHS has made recommendations related to the federal government's use of standards (the Consolidated Health Informatics standards) and, more recently, projects with the American Health Information Community and Office of the National Coordinator for Health Information Technology.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Not applicable

### **Key Documents and Reports**

NCVHS Reports and Recommendations: <http://www.ncvhs.hhs.gov/reptrecs.htm>

### **Web Site**

The National Committee on Vital and Health Statistics Web site: [www.ncvhs.hhs.gov](http://www.ncvhs.hhs.gov)

### **For More Information**

Debbie M. Jackson  
Senior Program Analyst  
National Center for Health Statistics, CDC  
3311 Toledo Road, Room 2339  
Hyattsville, MD 20782  
Telephone: (301) 458-4614

### **Reviewed**

Yes







# National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT)

## Sector

Health care

## Type of Standard

Data Interoperability Standard

## Sponsor

National Council for Prescription Drug Programs

## Purpose

NCPDP creates and promotes data interchange standards for the pharmacy services sector of the healthcare industry. As needs within the industry are identified, standards are updated to a new version or release. The most relevant standard for exchanging patient health information is NCPDP's SCRIPT standard. SCRIPT was developed for transmitting prescription information electronically between prescribers, providers, and other entities. The standard addresses the electronic transmission of new prescriptions, changes of prescriptions, prescription refill requests, prescription fill status notifications, cancellation notifications, relaying of medication history, and transactions for long-term care.

## Version

Version 1.0 Release 6

## Year Current Version Was Adopted

2008

## Age of Standard

Unknown

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services will provide incentives for e-Prescribing that complies with NCPDP SCRIPT, along with a variety of other NCPDP and other organization standards.

## Who Uses

Prescribers, providers, and other entities



## **Mandatory/Voluntary (and Authorization)**

Voluntary

Beginning in 2009, the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) requires the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services to provide incentives for e-Prescribing that complies with NCPDP SCRIPT, along with a variety of other NCPDP and other organization standards.

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

NCPDP is an ANSI-accredited Standards Development Organization. Currently, these NCPDP standards have been approved as an American National Standard (ANSI).

## **Type of Content**

Prescription information

## **Unit of Collection**

Patient

## **Data Availability**

Unknown

## **Relationship to other Standards**

Unknown

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Yes

## **Key Documents and Reports**

A Basic Guide to Standards: [http://www.ncdp.org/pdf/Basic\\_guide\\_to\\_standards.pdf](http://www.ncdp.org/pdf/Basic_guide_to_standards.pdf)

CMS Memo regarding standards: [http://www.cms.hhs.gov/PrescriptionDrugCovContra/Downloads/MemoERx\\_09.19.08.pdf](http://www.cms.hhs.gov/PrescriptionDrugCovContra/Downloads/MemoERx_09.19.08.pdf)





### **Web Site**

National Council for Prescription Drug Programs, Inc. (NCPDP) Web site: <http://www.ncdp.org/>

### **For More Information**

Patsy McElroy, Manager, Standards Development  
National Council for Prescription Drug Programs, Inc.  
9240 E. Raintree Drive  
Scottsdale, AZ 85260  
830-438-8055  
Telephone: (480) 477-1000  
Facsimile: (480) 767-1042  
E-mail: [pmcelroy@ncdp.org](mailto:pmcelroy@ncdp.org) or [ncdp@ncdp.org](mailto:ncdp@ncdp.org)

### **Reviewed**

No





## National eHealth Collaborative (NeHC)

### Sector

Health care

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

National eHealth Collaborative (NeHC)

### Purpose

National eHealth Collaborative (formerly called the American Health Information Community) is responsible for accelerating and coordinating current NeHC interoperability initiatives, including harmonizing and certifying standards of health IT; prioritizing stakeholder requirements for nationwide health IT interoperability; advancing the harmonization of technology standards and policies; enabling the NHIN (a “network of networks”); and addressing certification. NeHC was the successful applicant responding to an HHS December 2007 Notice of Funding Availability for a public-private successor to the public AHIC.

### Version

NeHC was incorporated in July 2008 and announced its new name January 2009.

### Year Current Version Was Adopted

NeHC is a harmonization body that currently has no harmonized standards.

### Age of Standard

NeHC is a harmonization body that currently has no harmonized standards.

### Federal Involvement/Endorsement

Funding to support NeHC comes from the U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. Federal representatives on AHIC Successor include those from: Secretary of U.S. Health and Human Services, Secretary of Veterans Affairs, the Office of the National Coordinator for Health Information Technology, and Veterans Health Administration.

### Who Uses

NeHC is a harmonization body that currently has no harmonized standards.



### **Mandatory/Voluntary (and Authorization)**

NeHC is a harmonization body that currently has no harmonized standards.

### **Estimate of Adoption**

NeHC is a harmonization body that currently has no harmonized standards.

### **Standards Development Process**

NeHC's 21-member Board of Directors ensures a unified voice representing the healthcare community; the Board is comprised of a majority of at-large members in addition to representational members, including consumers and the federal government. The Board of Directors will continue to mature the organization, setting direction for membership outreach and putting in place committees and workgroups to further the goal of nationally harmonizing health IT standards and improving the health of all Americans.

### **Type of Content**

NeHC is a harmonization body that currently has no harmonized standards.

### **Unit of Collection**

NeHC is a harmonization body that currently has no harmonized standards.

### **Data Availability**

NeHC is a harmonization body that currently has no harmonized standards.

### **Relationship to other Standards**

NeHC is a harmonization body that currently has no harmonized standards.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

NeHC is a harmonization body that currently has no harmonized standards.

### **Key Documents and Reports**

Bylaws Of NeHC: [http://www.ahicsuccessor.org/hhs/ahic.nsf/AHIC\\_Successor\\_Draft\\_Bylaws1\\_1.pdf](http://www.ahicsuccessor.org/hhs/ahic.nsf/AHIC_Successor_Draft_Bylaws1_1.pdf)

### **Web Site**

NeHC Web site: <http://www.nationalehealth.org>





**For More Information**

Meryt McGindley  
Acting Communications Director  
NeHC  
1940 Duke Street, Suite 200  
Alexandria, VA 22314  
Telephone: (877) 835-6506  
Facsimile: (703) 486-5753  
E-mail: [mmcgindley@nationalehealth.org](mailto:mmcgindley@nationalehealth.org)

**Reviewed**

No







## Nationwide Health Information Network (NHIN)

### Sector

Health care

### Type of Standard

Overarching Framework

### Sponsor

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology

### Purpose

The Nationwide Health Information Network (NHIN) aims to implement existing standards, including those standards recognized by U.S. Department of Health and Human Services, and to inform the standards development process. NHIN is being developed to provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and health care. This critical part of the national health IT agenda will enable health information to follow the consumer, be available for clinical decision making, and support appropriate use of healthcare information beyond direct patient care so as to improve health. ONC is advancing the development of the NHIN using a three-phased approach:

- Prototype Architectures
- Trial Implementations
- Production—a phased approach to move the NHIN toward production

### Version

In development

### Year Current Version Was Adopted

In development

### Age of Standard

In development

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology

**Who Uses**

Healthcare providers, patients, and others

**Mandatory/Voluntary (and Authorization)**

In development

**Estimate of Adoption**

November 10, 2005, HHS Secretary Mike Leavitt announced the award of contracts totaling \$18.6 million to four groups of healthcare and health information technology organizations to develop prototypes for a Nationwide Health Information Network architecture. Building upon the work of these Prototype Architectures, in September 2007, the Department of Health and Human Services awarded contracts totaling \$22.5 million to nine health information exchanges to begin trial implementations of the Nationwide Health Information Network, with an additional six grants totaling \$600,000 added in April 2008.

**Standards Development Process**

Recognition by the Secretary of HHS is critical to advancing both federal and private sector use of health IT standards as specified above. In order to ensure that software developers have adequate time to implement recognized standards in their software, Secretary Leavitt has established a two-step process for his recognition of interoperability standards. First, the Secretary publicly “accepts” standards recommended to him by the American Health Information Community and then, 1 year after his “acceptance,” the Secretary has committed to formal “recognition” of these standards.

The intervening year between “acceptance” and “recognition” of interoperability standards allows software developers time to test the implementation of standards and allows the Health Information Technology Standards Panel to refine the implementation guidance for how the standards need to be implemented based on feedback from actual software implementation. Only minimal changes of any kind may be implemented in the final 6 months before recognition, to ensure that software developers have a clear and stable target for their implementation efforts.

**Type of Content**

Patient health information between regional information exchanges

**Unit of Collection**

Patient

**Data Availability**

In development





### **Relationship to other Standards**

Fortunately, because of 42 CFR Part 2, many EHR-s currently support granular consent and “break the glass.” However, opponents point out that most legacy EHR-s do not. Of course, without granular consent, “break the glass” is just business as usual, and probably without an audit trail. The essential problem is who will pay for upgrading or replacing these legacy systems? SAMHSA wants HITSP to make granular consent a NHIN messaging standard. Legacy EHR-s may only support “role-based” access control (for example, only physicians can see detailed PHI) in the near future, but because privacy concerns in this country go well beyond behavioral health, a strong NHIN standard could eventually become a gold standard for all health care.

Future Plans

Unknown

### **Vendors Incorporating In Products**

In development

### **Key Documents and Reports**

Nationwide Health Information Network (NHIN): Prototype Architectures:

<http://www.hhs.gov/healthit/healthnetwork/prototype>

Nationwide Health Information Network (NHIN): Trial Implementations:

<http://www.hhs.gov/healthit/healthnetwork/trial>

### **Web Site**

U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology NHIN Web site: <http://www.hhs.gov/healthit/healthnetwork/background>

### **For More Information**

Mariann Yeager

Office of the National Coordinator for Health Information Technology

Telephone: (202) 205-8658

E-mail: [mariann.yeager@hhs.gov](mailto:mariann.yeager@hhs.gov)

### **Reviewed**

Yes





# Ryan White Program

## Sector

Health care

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Health and Human Services, Health Resources and Services Administration

## Purpose

U.S. Department of Health and Human Services, Health Resources and Services Administration published a Special Projects of National Significance Program New Competition (Catalog of Federal Domestic Assistance Number: 93.928) on November 25, 2008 to “support organizations funded under Parts C & D of the Ryan White HIV/AIDS Treatment and Modernization Act of 2006 that will promote the development of standard electronic client information data systems to improve the ability of grantees to report client-level data to the Department of Health and Human Services”

<https://grants.hrsa.gov/webexternal/FundingOppDetails.asp?FundingCycleId=0C11C382-7456-48BF-B70E-B75C5697264D&ViewMode=EU&GoBack=&PrintMode=&OnlineAvailabilityFlag=True&pageNumber=1>

## Version

To be developed

## Year Current Version was Adopted

To be developed

## Age of Standard

To be developed

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Health Resources and Services Administration

## Who Uses

Grantees funded under Part C Early Intervention Services (EIS) Programs and Part D, Coordinated HIV Services and Access to Research for Women, Infants, Children, and Youth Programs and Youth Services Initiative Program



## **Mandatory/Voluntary (and Authorization)**

Unknown

Public Health Service Act as amended, Section 2691, (42 USC 300ff-101)

## **Estimate of Adoption**

To be developed

## **Standards Development Process**

To be developed

## **Type of Content**

- Client characteristics such as gender, age, race/ethnicity, insurance type, homelessness, and so forth;
- Service utilization including core services: outpatient/ambulatory health services, oral health care, early intervention services (Parts C and D), health insurance premium and cost sharing assistance, home health care, home and community-based health services, hospice services, mental health services, medical nutrition therapy, medical case management (including treatment adherence), and substance abuse services-outpatient;
- Support services: case management (non-medical), child care services, developmental assessment/early intervention services, emergency financial assistance, food bank/home-delivered meals, health education/risk reduction, housing services, legal services, linguistic services, transportation services, outreach services, permanency planning, psychosocial support services—other, referral for health care/supportive services, rehabilitation services, respite care, substance abuse services—residential, and treatment adherence counseling;
- Health indicators such as HIV/AIDS status HIV infection, or CDC-defined AIDS, CD4+ Counts, Viral Load Testing, mortality status, TB status, substance abuse and mental health history, medication history, preventive therapy, and pregnancy history.

## **Unit of Collection**

Client-level data submission requirements begin in FY 2009

## **Data Availability**

To be developed

## **Relationship to other Standards**

To be developed





## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

To be developed

## **Key Documents and Reports**

Special Projects of National Significance Program New Competition announcement: <https://grants.hrsa.gov/webexternal/FundingOppDetails.asp?FundingCycleId=0C11C382-7456-48BF-B70E-B75C5697264D&ViewMode=EU&GoBack=&PrintMode=&OnlineAvailabilityFlag=True&pageNumber=1>

## **Web Site**

U.S. Department of Health and Human Services, Health Resources and Services Administration Ryan White Program Web site: <http://hab.hrsa.gov>

## **For More Information**

Adan Cajina, Branch Chief  
Demonstration and Evaluation Branch  
Health Resources and Services Administration  
U.S. Department of Health and Human Services  
5600 Fishers Lane, Room 7C-07  
Rockville, MD 20857  
Telephone: (301) 443-3180  
Facsimile: (301) 594-2511  
E-mail: [acajina@hrsa.gov](mailto:acajina@hrsa.gov)

## **Reviewed**

No







## **SCHIP Statement of Expenditures (CMS-21)**

### **Sector**

Health care

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### **Purpose**

The Quarterly State Children's Health Insurance Program (SCHIP) Statement of Expenditures for Title XXI (Form CMS-21) is the state's accounting statement of actual recorded expenditures and the disposition of federal funds

### **Version**

Unknown

### **Year Current Version was Adopted**

Unknown

### **Age of Standard**

Unknown

### **Federal Involvement/Endorsement**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services

### **Who Uses**

States. The WEB-based Medicaid and SCHIP Budget and Expenditure System (MBES/CBES) has allowed the states to electronically submit their Form CMS-21 directly to the CMS Data Center and the Medicaid/SCHIP database. When using the MBES/CBES, states do not have to submit a hard copy of the signed certification statement to CMS. CMS has modified the MBES/CBES to allow states to complete the signature/certification form through the MBES/CBES and transmit this form to them. Signed hard copies must be maintained at the state.



## **Mandatory/Voluntary (and Authorization)**

Mandatory

States must submit each quarter under Title XXI

## **Estimate of Adoption**

As a mandatory reporting standard, it is expected that adoption is high.

## **Standards Development Process**

Unknown

## **Type of Content**

Expenditures reported on this form primarily include those made to initiate and expand health insurance coverage to uninsured, low-income children through a separate SCHIP. Administrative costs associated with expanding child health insurance coverage to uninsured, low-income children through an expansion of a state Medicaid program may also be included on the Form CMS-21 if the state opts to claim Federal Financial Participation at the enhanced Federal Medical Assistance Percentage. Program services costs associated with expanding child health insurance coverage to uninsured, low-income children through an expansion of a State Medicaid program are not reported on the Form CMS-21.

## **Unit of Collection**

Program expenditure

## **Data Availability**

Various reports and data files are available at: [http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02\\_CMS21.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02_CMS21.asp#TopOfPage)

## **Relationship to other Standards**

Unknown

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Copies of forms, summary state-by-state total expenditures by program for the Medicaid Program, Medicaid





Administration and SCHIP programs and summary state-specific data from the CMS-64 and the CMS-21:  
[http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02\\_CMS21.asp](http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02_CMS21.asp)

### **Web Site**

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services SCHIP site:  
[http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02\\_CMS21.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidSCHIPBudExpInfSys/02_CMS21.asp#TopOfPage)

### **For More Information**

Rosemarie Hakim  
Office of Research, Development, and Information  
Centers for Medicare and Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244  
Telephone: (410) 786-3934  
E-mail: [Rosemarie.hakim@cms.hhs.gov](mailto:Rosemarie.hakim@cms.hhs.gov)

### **Reviewed**

No



Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# HOUSING/ SHELTER





## Client Activity Reporting System (CARS)

### **Sector**

Housing/Shelter

### **Type of Standard**

Reporting Requirements or Reporting Standards

### **Sponsor**

U.S. Department of Housing and Urban Development, Federal Housing Administration

### **Purpose**

CARS is a HUD database that will receive data from client management systems for use by HUD.

### **Version**

Unknown

### **Year Current Version Was Adopted**

Unknown

### **Age of Standard**

Unknown

### **Federal Involvement/Endorsement**

U.S. Department of Housing and Urban Development, Federal Housing Administration

### **Who Uses**

HUD is requiring that agencies use a CMS to capture client-level data for a series of specified data fields and that this CMS have an interface with HUD's CARS database. In other words, HUD is asking agencies to enter basic client information into a CMS that is capable of transmitting that information electronically to HUD. Electronic files allow HCAs submittals in required data fields at the touch of a button. The agencies will no longer have to report manually through HUD's Housing Counseling System (HCS).





## **Mandatory/Voluntary (and Authorization)**

Mandatory

Pending publication of a final rule [Docket No. FR-4798-F-02], beginning October 1, 2007, all Housing Counseling Agencies (HCAs) participating in HUD's Housing Counseling Program will be required to use a Client Management System (CMS) that interfaces with HUD's databases in order to collect and submit agency and client-level data.

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

Unknown

## **Type of Content**

Client characteristics, counseling activities, and session outcomes

## **Unit of Collection**

Individual

## **Data Availability**

Unknown

## **Relationship to other Standards**

Unknown

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Several CMS vendors are working toward satisfying HUD's requirements and their systems have been successfully tested in interfacing with HUD's system. Counseling agencies are encouraged to learn about, and choose from, HUD's list of CMS compliant vendors: [http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA\\_HOME/COUNSELORS/DOCUMENTS/CMSVL031307.PDF](http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA_HOME/COUNSELORS/DOCUMENTS/CMSVL031307.PDF)

## **Key Documents and Reports**

Data Requirements: Summary of data fields that agencies will be required to transmit: [http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA\\_HOME/COUNSELORS/ASSISTANCE/DATA\\_REQUIREMENTS/CDFR100206.DOC](http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA_HOME/COUNSELORS/ASSISTANCE/DATA_REQUIREMENTS/CDFR100206.DOC)





Client Activity Reporting System (CARS) Frequently Asked Questions (FAQ):

<http://www.hud.gov/offices/hsg/sfh/hcc/carsfaq.pdf>

HUD CARS disclosure statement: [http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA\\_HOME/COUNSELORS/DOCUMENTS/CARSDS031407.PDF](http://portal.hud.gov/portal/pls/portal/docs/PAGE/FHA_HOME/COUNSELORS/DOCUMENTS/CARSDS031407.PDF)

### **Web Site**

U.S. Department of Housing and Urban Development Client Management System Requirement Guidance for Housing Counseling Agencies: <http://www.hud.gov/offices/hsg/sfh/hcc/hccprof21.cfm>

### **For More Information**

Ruth Roman, Director, Office of Program Support,  
Office of Housing, Department of Housing and Urban Development,  
451 Seventh Street SW, Room 9274  
Washington, DC 20410-8000  
Telephone: (202) 708-0317  
E-mail: [ruth\\_roman@hud.gov](mailto:ruth_roman@hud.gov)

### **Reviewed**

No





## Form HUD-50058

### Sector

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Housing and Urban Development, Office of Public and Indian Housing

### Purpose

Form-50058 is a module of the Office of Public and Indian Housing Information Center (PIC) system that collects, stores, and generates reports on families who participate in Public Housing or Section 8 rental subsidy programs. The data collected on Form HUD-50058 provides U.S. Department of Housing and Urban Development (HUD) with a picture of the people who participate in subsidized housing programs. Form HUD-50058 collects and validates tenant data uploaded by Housing Authorities who report on families who participate in Public Housing or Section 8 rental subsidy programs. The Public and Indian Housing Information Center (PIC) system then captures this information and creates reports used to:

- analyze the subsidized housing programs,
- monitor Public Housing Authorities,
- detect fraud, and
- provide information to Congress and other interested parties.

### Version

2004

### Year Current Version Was Adopted

2004

### Age of Standard

1999

### Federal Involvement/Endorsement

U.S. Department of Housing and Urban Development, Office of Public and Indian Housing





### **Who Uses**

Public Housing Agencies are required to submit Form HUD-50058 data at least annually for each household that participates in Public and Indian Housing assisted housing programs. Public Housing Agencies must electronically submit all Form HUD-50058 data to the PIC System.

### **Mandatory/Voluntary (and Authorization)**

Reporting by Public Housing Agencies is mandatory.

### **Estimate of Adoption**

As a mandated reporting requirement, it is believed to be widely adopted.

### **Standards Development Process**

Unknown

### **Type of Content**

Household socioeconomic demographics, type of assistance accessed

### **Unit of Collection**

Household

### **Data Availability**

The Resident Characteristics Report summarizes general information about households who reside in Public Housing or who receive Section 8 assistance. The report provides aggregate demographic and income information that allows for an analysis of the scope and effectiveness of housing agency operations. The data used to create the report is updated once a month from IMS-PIC. At this time, the Resident Characteristics Report is available via a public Web page: <https://pic.hud.gov/pic/RCRPublic/rcrmain.asp>

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Yes





## **Key Documents and Reports**

Form HUD-50058 Technical Reference Guide: <http://www.hud.gov/offices/pih/systems/pic/50058/pubs/trg>

User Manual: <http://www.hud.gov/offices/pih/systems/pic/userguides.cfm#50058>

## **Web Site**

The PIC Form-50058 Web site: <http://www.hud.gov/offices/pih/systems/pic/50058/index.cfm>

## **For More Information**

Orlando J. Cabrera  
Assistant Secretary for Public and Indian  
Housing  
Office of Public and Indian Housing  
U.S. Department of Housing and Urban Development  
451 Seventh Street SW  
Washington, DC 20410  
Telephone: (202) 708-1112

## **Reviewed**

No





# Homeless Management Information System XML (HUD HMIS XML)

**Sector**

Housing/Shelter

**Type of Standard**

Data Interoperability Standard

**Sponsor**

U.S. Department of Housing and Urban Development, Office of Community Planning and Development

**Purpose**

Homeless Management Information System XML (HUD HMIS XML) standardizes the data transmission payload format for homeless personal identifiers, demographics, services, and program participation.

**Version**

HMIS XML Schema version 2.8

**Year Current Version Was Adopted**

2008

**Age of Standard**

2005

**Federal Involvement/Endorsement**

U.S. Department of Housing and Urban Development, Office of Community Planning and Development

**Who Uses**

Organizations receiving funding through HUD's McKinney homeless assistance programs.

**Mandatory/Voluntary (and Authorization)**

Use of the HMIS XML Schema is voluntary. However, utilization of an HMIS system is mandatory.

Congressional direction in the Conference Report (H.R. Report 106-988) on the FY 2001 HUD Appropriations Act required HUD to report to the Appropriations Committees on its strategy for collecting data on homelessness. In Public Law 109-115 reiterated its support for the HMIS initiative and the development of a report on homelessness.





## **Estimate of Adoption**

As a mandatory standard, it is expected that adoption is high. Over 90 percent of the Local Continuums of Care are collecting client-level data in their HMIS. But the rate of adoption of HMIS XML Schema is much lower and largely unknown.

## **Standards Development Process**

There is no formal process. Currently, HUD HMIS Technical Assistance providers manage the review and release of new versions. A forum at [HMIS\\_Data\\_Integration@googlegroups.com](mailto:HMIS_Data_Integration@googlegroups.com) allows for developer and community input and discussion of use and change requests for the HMIS Schema.

## **Type of Content**

Client personal identifying information such as: name, Social Security number, and date of birth; demographic information, such as ethnicity, race, and gender; intake assessment data such as veteran status, disabling condition, residence prior to program entry, zip code of last permanent address; program participation and service data such as program entry and exit dates, Alliance of Information Services (AIRS) taxonomy service and need codes; case information; and household relationships and membership. All major data types are indexed and time stamped.

## **Unit of Collection**

Individual or Household

## **Data Availability**

Access to client data must be negotiated separately with each HUD designated Continuum of Care (CoC), and is generally not shared, save for limited authorized uses. HUD does not receive client-level data from the CoC, so only aggregate information submitted to HUD by the CoC using the HUD HMIS Annual Homeless Assessment Report (AHAR) schema version 1.0 is available from HUD. The AHAR, based on HMIS data from a nationally representative sample of jurisdictions, is collected and annually reported to Congress.

## **Relationship to other Standards**

HMIS XML refers service codes in the LA 211/AIRS Taxonomy of Health and Human Services and imports data types from the AIRS XML Schema.

## **Future Plans**

Potential future directions include:

- HMIS automated client record synchronization between systems using Web messaging.
- Reconfiguration as a subcomponent of Human Services XML (HSXML).
- Importation of data types from the Disaster Client Data Standard (DCDS).





- Harmonization of client data types with OASIS Customer Information Quality (CIQ) standard.
- Integration with the OASIS Emergency Data eXchange Language (EDXL) and the National Information Exchange Model (NIEM).

### **Vendors Incorporating In Products**

Yes. Communities can choose to use one of over 25 software vendors that serve the market or deploy a custom solution. Approximately 75 percent of implementations use one of five software vendors; 21 percent use custom-designed systems. Vendor adoption levels of the HMIS Schema as an import and export payload format is unknown.

### **Key Documents and Reports**

HMIS XML Schema Package version 2.8: <http://www.hmis.info/Resources/View/ViewResource.aspx?id=919&AspxAutoDetectCookieSupport=1>

Report to Congress (2007): Sixth Progress Report on HUD's Strategy for Improving Homeless Data Collection, Reporting and Analysis: <http://www.hud.gov/offices/cpd/homeless/library/improvingDataCollection.pdf>

### **Web Site**

HUD HMIS Web site: <http://www.hud.gov/offices/cpd/homeless/hmis/index.cfm>

### **For More Information**

Julie Hovden  
Special Needs Program Specialist  
HUD Office of Special Needs Programs  
U.S. Department of Housing and Urban Development  
451 Seventh Street SW, Room 7262  
Washington, DC 20410  
Telephone: (202) 708-4300, ext. 4496  
E-mail: Julie\_Hovden@hud.gov

### **Reviewed**

Yes





# Low Income Home Energy Assistance (LIHEAP) Program Performance

## Sector

Housing/Shelter

## Type of Standard

Reporting Requirements or Reporting Standards —LIHEAP Household Report, LIHEAP Grantee Survey, LIHEAP Supplemental Sample to the Residential Energy Consumption Survey (RECS) conducted by the U.S. Energy Administration, and low-income household data derived from the American Community Survey (ACS) conducted by the Census Bureau.

## Sponsor

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Community Services, Division of Energy Assistance

## Purpose

The mission of the Low Income Home Energy Assistance Program (LIHEAP) is to assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs. LIHEAP program performance is measured through the Office of Management and Budget's (OMB's) Program Assessment Rating Tool (PART). The measurement data influences OCS programmatic efforts to improve program performance.

## Version

2003

## Year Current Version Was Adopted

2003

## Age of Standard

2003

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Administration for Children and Families, Office of Community Services, Division of Energy Assistance

## Who Uses

The Department of Health and Human Services, Office of Management and Budget, and State LIHEAP Grantees



## **Mandatory/Voluntary (and Authorization)**

Mandatory under the Government Performance and Results Act of 1993

## **Estimate of Adoption**

Reporting Standard is mandatory for state LIHEAP Grantees and voluntary for household participants interviewed in the RECS and the ACS.

## **Standards Development Process**

The goals and measures were developed by the Office of Community Services through a consultative process with state and local LIHEAP officials prior to the implementation of OMB's PART.

## **Type of Content**

Household characteristics such as: number of households assisted by type of LIHEAP assistance; assisted household poverty level; presence in assisted households of at least one member who is elderly, disabled, or a young child; LIHEAP administrative costs; household income; household energy expenditures; and LIHEAP benefits. Energy burden data are derived from the RECS. Data on income eligible households are derived from the ACS. Performance measures include LIHEAP reciprocity targeting indexes, home energy burden targeting indexes, and program efficiency.

## **Unit of Collection**

Aggregated household data from state LIHEAP Reports and Surveys, and microdata sets from RECS and ACS.

## **Data Availability**

The data from the LIHEAP Grantee Survey and the LIHEAP Household Report are included in the LIHEAP Report to Congress and are available at: <http://www.acf.hhs.gov/programs/ocs/liheap/publications/index.html#report>

The LIHEAP Home Energy Notebook supplements the annual LIHEAP Report to Congress:  
[www.acf.hhs.gov/programs/ocs/liheap/publications/index.html#notebook](http://www.acf.hhs.gov/programs/ocs/liheap/publications/index.html#notebook)

OCS' LIHEAP Clearinghouse also maintains a library of its publications on a variety of LIHEAP topics:  
<http://liheap.ncat.org/pub.htm>

## **Relationship to other Standards**

ACF's Strategic Performance Plan





## **Future Plans**

Identifying LIHEAP outcome performance measures

## **Vendors Incorporating In Products**

APPRISE developed Federal LIHEAP targeting indexes.

## **Key Documents and Reports**

LIHEAP Grantee Household Report Form (FY 2008): [www.acf.hhs.gov/programs/ocs/liheap/grantees/forms.html#household\\_report](http://www.acf.hhs.gov/programs/ocs/liheap/grantees/forms.html#household_report)

LIHEAP Grantee Survey Form (FY 2008):  
[www.acf.hhs.gov/programs/ocs/liheap/grantees/forms.html#grantee\\_survey](http://www.acf.hhs.gov/programs/ocs/liheap/grantees/forms.html#grantee_survey)

LIHEAP's Performance Measurement:  
[http://www.acf.hhs.gov/programs/ocs/liheap/program\\_stats/index.html#pm](http://www.acf.hhs.gov/programs/ocs/liheap/program_stats/index.html#pm)

Managing for Results Primer: [http://www.acf.hhs.gov/programs/ocs/liheap/program\\_stats/primer.html](http://www.acf.hhs.gov/programs/ocs/liheap/program_stats/primer.html)

## **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families, Low Income Home Energy Assistance Program Web site: <http://www.acf.hhs.gov/programs/ocs/liheap/index.html>

## **For More Information**

Leon Litow  
Lead Program Analyst  
Division of Energy Assistance, OCS  
370 L'Enfant Promenade SW  
Washington, DC 20447  
Telephone: (202) 401-5304  
Facsimile: (202) 401-5661  
E-mail: [llitow@acf.hhs.gov](mailto:llitow@acf.hhs.gov)

## **Reviewed**

Yes





# Weatherization Assistance Program

## Sector

Housing/Shelter

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Energy, Office of Energy and Renewable Energy

## Purpose

The U.S. Department of Energy's (DOE) Weatherization Assistance Program (Weatherization) reduces energy costs for low-income households by increasing the energy efficiency of their homes, while ensuring their health and safety. The Program provides energy-efficiency services to more than 100,000 homes every year, reducing average annual energy costs by \$413 or more per household. The Program prioritizes services to the elderly, people with disabilities, and families with children. These low-income households are often on fixed incomes or rely on income assistance programs and are most vulnerable to volatile changes in energy markets. "High energy users" or households with a high energy burden may also receive priority.

## Version

Unknown

## Year Current Version was Adopted

Unknown

## Age of Standard

1976

## Federal Involvement/Endorsement

U.S. Department of Energy, Office of Energy and Renewable Energy

## Who Uses

DOE works in partnerships with state and local-level agencies to implement the Program. The DOE Project Management Center (PMC) awards grants to state-level agencies, which then contract with local agencies. Weatherization programs operate in all 50 states, the District of Columbia, among Native American tribes, and anticipate servicing the U.S. territories beginning in





Program Year 2009. Approximately 900 local agencies deliver Weatherization services to eligible residents in every county in the nation. Grantees use WinSAGA to generate customized reporting.

**Mandatory/Voluntary (and Authorization)**

The reporting requirements are set forth in Attachment 2 of Funding Opportunity Announcement No. DE-PS26-09NT01243.

**Estimate of Adoption**

Unknown

**Standards Development Process**

Unknown

**Type of Content**

Unknown

**Unit of Collection**

Weatherized unit

**Data Availability**

Unknown

**Relationship to other Standards**

Unknown

**Future Plans**

Unknown

**Vendors Incorporating In Products**

Unknown

**Key Documents and Reports**

Unknown

**Web Site**

Department of Energy Weatherization Program Web site: <http://www.waptac.org>





**For More Information**

Gil Sperling, Program Manager  
Office of Weatherization and Intergovernmental Program  
1000 Independence Avenue SW, EE-2K  
Forrestal Building  
Washington, DC 20585-0121  
Telephone: (202) 587-1644  
Facsimile: (202) 586-1233  
E-mail: [Gil.Sperling@ee.doe.gov](mailto:Gil.Sperling@ee.doe.gov)

**Reviewed**

No





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# INCOME SUPPORT





# Temporary Assistance for Needy Families (TANF) and Tribal TANF

## Sector

Income Support

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Health and Human Services, Administration for Children and Families

## Purpose

The Temporary Assistance for Needy Families (TANF) and Tribal TANF are designed to help needy families achieve self-sufficiency. HHS collects the information electronically through the use of the TANF Data Report (ACF-199) and the SSP-MOE Data Report (ACF-209). Since 1996, federally recognized American Indian Tribes and Alaska Native organizations have been allowed to operate their own TANF programs and serve tribal members who would otherwise be served by the state in which they live.

## Version

2006

## Year Current Version Was Adopted

2006

## Age of Standard

Unknown

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Administration for Children and Families

## Who Uses

State and Tribal TANF agencies complete a TANF data collection form for all families receiving assistance under the TANF program. Data are collected on a monthly basis and submitted quarterly to the national TANF databases. Research databases are compiled for an entire fiscal year. TANF case record information is reported to the national TANF database by states and territories on a quarterly basis. The database consists of active cases (families who were receiving assistance for the reporting month by the end of the sample month) and closed cases (families whose assistance was terminated for the reporting month, but received assistance in the prior month). States have the option of submitting all active and closed cases or a sample of these cases.

**Mandatory/Voluntary (and Authorization)****Mandatory**

The Deficit Reduction Act of 2005 reauthorized the Temporary Assistance for Needy Families (TANF) program and required the Secretary to regulate in certain areas to ensure a more uniform and consistent measurement of the work participation rates. The Interim Final Rule was published on June 29, 2006. States, the District of Columbia and certain U.S. territories are required by 42 U.S.C. 611 and 45 CFR Part 265 to collect on a monthly basis and report to HHS on a quarterly basis a wide variety of disaggregated case record information for their programs funded under Temporary Assistance for Needy Families (TANF).

**Estimate of Adoption**

As a mandatory reporting standard, it is expected that adoption is high.

**Standards Development Process****Unknown****Type of Content**

The TANF database contains demographic characteristics for families receiving assistance under the TANF program.

**Unit of Collection**

Individual level and family level. However, states and tribes have the option of providing a sample of cases, rather than the complete data set. There is no single sampling method applied across the board for all states submitting data to the national TANF database. Twenty-nine states and tribes submitted records on all active and closed cases, while the remaining 24 states and tribes submitted sample data. If states do not meet the annual minimal sample size requirements, they must report data for all active and closed cases. No tribe has a caseload large enough to warrant sampling. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 requires states, territories, and tribes to collect on a monthly basis and report to the Secretary of the Department of Health and Human Services on a quarterly basis disaggregated case record information on families receiving assistance, families no longer receiving assistance, and families newly approved for assistance from programs funded under TANF.

**Data Availability**

U.S. Department of Health and Human Services regularly creates reports from data submitted through this program: [http://www.hhs-stat.net/scripts/topic.cfm?start=91&page\\_no=10&id=330](http://www.hhs-stat.net/scripts/topic.cfm?start=91&page_no=10&id=330)

TANF Reports to Congress are available at: <http://www.acf.hhs.gov/programs/ofa/data-reports/index.htm#annualreport>





### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Program Instruction: Electronic Submission of Annual Report on TANF Programs (Attachment A) and State Maintenance-of-Effort (MOE) Programs (Form ACF-204) (Attachment B): <http://www.acf.hhs.gov/programs/ofa/policy/pi-ofa/2008/200806/pi200806.pdf>

Information Memorandum: Income Status, Unemployment Rates, Economic Assistance Program Participation Rates, and Measures of Well-being for Families/Households: <http://www.acf.hhs.gov/programs/ofa/data-reports/tanfedit/IM06TRnFle.htm>

### **Web Site**

U.S. Department of Health and Human Services, Administration for Children and Families TANF Web site: <http://www.acf.hhs.gov/programs/ofa/tanf/index.html>

### **For More Information**

Moniquin Huggins, Acting Associate Director  
Child Care Bureau  
Office of Family Assistance  
U.S. Department of Health and Human Services  
370 L'Enfant Promenade SW, Fifth Floor East  
Washington, DC 20447  
Telephone: (202) 690-8490  
Facsimile: (202) 690-5600  
E-mail: [moniquin.huggins@acf.hhs.gov](mailto:moniquin.huggins@acf.hhs.gov)

### **Reviewed**

No





Understanding Human Services Utilization:  
Opportunities for Data Sharing between Federally Funded Programs



# PUBLIC HEALTH





## Disaster Surveillance Forms

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

The Centers for Disease Control and Prevention's (CDC) Disaster Surveillance Workgroup (DSWG) has developed forms for public health surveillance after a disaster. Individuals completing these forms should submit them to the appropriate state or local public health authorities. State or local public health authorities are invited to modify contact information on these forms as needed for reporting within their jurisdiction. CDC is interested in receiving completed forms after they have been submitted to, or reviewed by, state or local agencies. The information derived through these surveillance efforts are used to identify events of public health concern among facilities and across states. They also assist in directing interventions and other resources to areas of greatest need, as well as guide future response efforts.

### Version

2

### Year Current Version Was Adopted

2008

### Age of Standard

2007

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention



## Who Uses

State or local public health authorities. Data collectors vary depending on the form:

- Environmental Health Shelter Assessment Tool - environmental health practitioners
- Disaster-Related Mortality Surveillance Form –medical examiners, coroners, hospitals, nursing homes, or funeral homes
- Natural Disaster Morbidity Report Form (Interim) - acute care facilities (for example, shelters with medical staff, hospitals)
- Abbreviated Natural Disaster Morbidity Report Form (Interim) - hospitals
- Individual Natural Disaster Morbidity Tally Form (Interim) - shelter facilities
- Aggregate Natural Disaster Morbidity Report Form (Interim) - acute care facilities (for example, shelters with medical staff, hospitals)

## Mandatory/Voluntary (and Authorization)

Voluntary

## Estimate of Adoption

Use of the form is voluntary. Several states have adopted the use of these forms and used them during the 2008 Hurricane season.

## Standards Development Process

The forms were developed by the CDC Disaster Surveillance Workgroup, which is a cross-agency working group tasked with creating standardized forms to be used following a natural disaster. External partners from the DSWG included state and local public health staff and federal partners (including American Red Cross, U.S. Public Health Service, and Department of Defense). Changes to the standards are regulated through the DSWG leadership.

## Type of Content

The CDC has the following forms:

- Environmental Health Shelter Assessment Tool—to assist environmental health practitioners in conducting a rapid assessment of shelter conditions during emergencies and disasters. The assessment form covers 14 general areas of environmental health, ranging from basic food safety and water quality to pet (companion animal) wellness and allows for the documentation of immediate needs in shelters.
- Disaster-Related Mortality Surveillance Form—to identify the number of deaths related to the disaster and provide basic mortality information. Setting: Form should be filled out by medical examiners, coroners, hospitals, nursing home, or funeral homes during a disaster. This form does not replace the death certificate.





Natural Disaster Morbidity Report Form (Interim)—to capture individual-level active surveillance of medical conditions when timely, detailed, patient-level information is needed for response efforts. Setting: Acute care facilities (for example, shelters with medical staff, hospitals).

Abbreviated Natural Disaster Morbidity Report Form (Interim)—an abbreviated version of the Natural Disaster Morbidity Report Form. Use this form if summary or less-detailed information is sufficient or when the burden of collecting detailed, individual information is substantial. Setting: Hospitals

Individual Natural Disaster Morbidity Tally Form (Interim)—an abbreviated version of the Natural Disaster Morbidity Report Form. Use this form if summary or less-detailed information is sufficient and a tally sheet is the most useful to capture morbidity data. This form captures morbidity data at the individual level but does not separate data by individual. Setting: Shelter facilities.

Aggregate Natural Disaster Morbidity Report Form (Interim)—to collect aggregate morbidity data. This form should be used for reporting purposes and does not capture individual-level data. Setting: Acute care facilities (for example, shelters with medical staff, hospitals)

### **Unit of Collection**

The units of collection for the forms are:

- Environmental Health Shelter Assessment Tool—shelters
- Disaster-Related Mortality Surveillance Form—individual
- Natural Disaster Morbidity Report Form (Interim)—individual
- Abbreviated Natural Disaster Morbidity Report Form (Interim)—individual
- Individual Natural Disaster Morbidity Tally Form (Interim)—individual level, but does not separate data by individual
- Aggregate Natural Disaster Morbidity Report Form (Interim)—aggregate morbidity data

### **Data Availability**

Data collected based on these forms is owned by the local jurisdiction where the data were collected.

### **Relationship to other Standards**

Unknown

### **Future Plans**

The DSWG continues to update these standardized forms. The DSWG meets regularly with its stakeholders (federal and local public health partners) to assess and modify the forms.



## **Vendors Incorporating In Products**

None

## **Key Documents and Reports**

Forms may be found at: <http://www.emergency.cdc.gov/disasters/surveillance>

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention Public Health Surveillance After a Disaster Web site: <http://www.emergency.cdc.gov/disasters/surveillance>

## **For More Information**

Amy Wolkin, MSPH, Acting Lead,  
Preparedness and Response Team, Health Studies Branch  
Centers for Disease Control and Prevention  
4770 Buford Highway, MS F57  
Atlanta, GA 30341  
Telephone: (770) 488-3402  
Facsimile: (770) 488-3450  
E-mail: [awolkin@cdc.gov](mailto:awolkin@cdc.gov)

## **Reviewed**

Yes





## Epidemic Information Exchange (Epi-X)

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

Epi-X is a Web-based communications solution for public health professionals. Through Epi-X, CDC officials, state and local health departments, poison control centers, and other public health professionals can access and share preliminary health surveillance information—quickly and securely. Users can also be actively notified of breaking health events as they occur. Epi-X offers scientific and editorial support, controlled user access, digital credentials and authentication, rapid outbreak reporting, and peer-to-peer consultation.

### Version

2000

### Year Current Version Was Adopted

2000

### Age of Standard

2000

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Who Uses

Participation in Epi-X is limited to public health officials designated by each health agency. These experts are engaged in identifying, investigating, and responding to health threats.

### Mandatory/Voluntary (and Authorization)

Voluntary







### **Estimate of Adoption**

Epi-X has approximately 4,200 users. Since its inception in December 2000, health officials have posted approximately 6,700 reports.

### **Standards Development Process**

Unknown

### **Type of Content**

Epi-X supports postings about disease outbreaks and other public health events that potentially involve multiple jurisdictions. Epi-X highlights include reports related to local and national responses to terrorism, SARS, and Hurricane Katrina. Other Epi-X reports have focused on West Nile virus surveillance, influenza surveillance and pandemic preparation, food borne outbreaks and food recalls that affected residents in multiple states, and investigations of travelers with contagious illnesses.

### **Unit of Collection**

Unknown

### **Data Availability**

Access to Epi-X is limited to designated officials to ensure the security necessary for the exchange of preliminary and provisional information. Epi-X users are designated by each state. Each official must obtain pre-approval from the appropriate health agency.

### **Relationship to other Standards**

Unknown

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Unknown

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention Epi-X Web site:  
<http://www.cdc.gov/epix>





**For More Information**

Robbie Michelle Locklar  
Epi-X Training and Support  
CDC Epidemic Information Exchange (Epi-X)  
U.S. Centers for Disease Control and Prevention  
Coordinating Center for Health Information and Service  
National Center for Health Marketing  
Telephone: (404) 639-5049 or (866) 720-3749  
E-mail: [epix@cdc.gov](mailto:epix@cdc.gov)

**Reviewed**

No





## Health Alert Network (HAN)

### Sector

Emergency/Disaster  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

The Health Alert Network (HAN) is intended to ensure that each community has rapid and timely access to emergent health information; a cadre of highly trained professional personnel; and evidence-based practices and procedures for effective public health preparedness, response, and service on a 24/7 basis.

The Health Alert Network will function as PHIN's Health Alert component. This includes collaborating with federal, state, and city/county partners to develop protocols and stakeholder relationships that will ensure a robust interoperable platform for the rapid exchange of public health information.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

1998

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Who Uses

Connected To HAN: 50 States, 3 large City Health Departments, 3 County Health Departments, 8 Territories, the District of Columbia, Health Organizations and Major Hospital Networks, local exemplar centers, academic centers, and specialty centers



## **Mandatory/Voluntary (and Authorization)**

Voluntary

All 50 states have funding for HAN goals pertaining to focus area “E” of the cooperative agreements

## **Estimate of Adoption**

A vast majority of the state-based HAN programs have over 90 percent of their population covered under the umbrella of HAN

## **Standards Development Process**

The CDC is collaborating with federal, state, and city/county partners to develop protocols and stakeholder relationships that will ensure a robust interoperable platform for the rapid exchange of public health information.

## **Type of Content**

Unknown

## **Unit of Collection**

Unknown

## **Data Availability**

Unknown

## **Relationship to other Standards**

HAN will continue to be an active asset in the overall PHIN Initiative.

## **Future Plans**

HAN will continue to be an active asset in the overall PHIN Initiative.

## **Vendors Incorporating In Products**

Unknown

## **Key Documents and Reports**

Unknown

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Health Alert Network Web site: <http://www2a.cdc.gov/han/Index.asp>





**For More Information**

Robb Chapman (CDC/CCHIS/NCPHI)  
National Center for Public Health Informatics  
Centers for Disease Control and Prevention  
1600 Clifton Road, MS E-68  
Atlanta, GA 30333  
Tel: (404) 498-6386  
Facsimile: (404) 498-6225  
E-mail: [rsc0@cdc.gov](mailto:rsc0@cdc.gov)

Reviewed

No







# National Electronic Disease Surveillance System (NEDSS)

## Sector

Emergency/Disaster  
Public Health

## Type of Standard

Reporting Requirements or Reporting Standards

## Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Integrated Health Information Systems in the Office of Director

## Purpose

The National Electronic Disease Surveillance System (NEDSS) is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state, and local levels. It is a major component of the Public Health Information Network (PHIN). NEDSS system architecture is designed to integrate and replace several current CDC surveillance systems, including the National Electronic Telecommunications System for Surveillance (NETSS), the HIV/AIDS reporting system, and the vaccine preventable diseases and systems for tuberculosis (TB) and infectious diseases.

## Version

In development

## Year Current Version Was Adopted

In development

## Age of Standard

NEDSS began in 2001

## Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Integrated Health Information Systems in the Office of Director

## Who Uses

Healthcare and public health organizations



**Mandatory/Voluntary (and Authorization)**

Voluntary

NEDSS, along with the Public Health Emergency Preparedness Cooperative Agreement, provides major financial support directly to state and local public health surveillance systems to develop or purchase integrated NEDSS-compatible applications.

**Estimate of Adoption**

Over 35 states have implemented surveillance systems based on the NEDSS vision.

**Standards Development Process**

NEDSS is a collaborative effort among state and local public health partners and numerous CDC staff and contractors. The success of NEDSS is dependent upon the assistance and expertise of these partners and the coordinated efforts of diverse scientific and public health disciplines. Using software development industry standards, formal processes for identifying the public health needs in the system (business requirements) are developed through Joint Application Development (JAD) sessions that involve all principal stakeholders which include state and local public health representatives associated with such national bodies as: The Council of State and Territorial Epidemiologists, The Association of State and Territorial Health Officials, The National Association of City and County Health Officials, The Association of Public Health Laboratories, The National Association of Public Health Statistics and Information Systems, The National Association of Health Data Organizations, and similar entities representing the needs of particular programmatic areas.

**Type of Content**

Unknown

**Unit of Collection**

Individual

**Data Availability**

In development

**Relationship to other Standards**

NEDSS system architecture is designed to integrate and replace several current CDC surveillance systems, including the National Electronic Telecommunications System for Surveillance (NETSS), the HIV/AIDS reporting system, and the vaccine preventable diseases and systems for tuberculosis (TB) and infectious diseases.





NEDSS relies heavily on industry standards (including standard vocabulary code sets such as LOINC, SNOWMED, and HL7).

### **Future Plans**

NEDSS will support standards-based PHIN and AHIC-approved electronic message exchange between public health stakeholders.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Base System Description—describes the vision, development, implementation, and uses of the NEDSS Base System as a component of the overall NEDSS initiative: <http://www.cdc.gov/nedss/BaseSystem/NEDSSBaseSysDescription.pdf>

Base System Fact Sheet: <http://www.cdc.gov/nedss/BaseSystem/NEDSSBasesysFactSheet.pdf>

System Specifications: <http://www.cdc.gov/nedss/BaseSystem/NEDSSRequirements.pdf>

System Architecture - Version 2.0 of the “Proposed Integrated Surveillance Systems Component Architecture”: <http://www.cdc.gov/nedss/BaseSystem/NEDSSsysarch2.0.pdf>

System Reference Tables: [http://www.cdc.gov/nedss/BaseSystem/Sys\\_Ref\\_Tables\\_101001.pdf](http://www.cdc.gov/nedss/BaseSystem/Sys_Ref_Tables_101001.pdf)

Business Discovery Statement - contains information regarding the NEDSS Base System and Program Area Modules (PAMs). Its purpose is to guide decisions regarding project scope, processes supported, and functionality for the project. The program area public health processes and the overall NEDSS vision provide the context for the Business Discovery Statement: [http://www.cdc.gov/nedss/BaseSystem/NEDSSBusinessDiscoveryStatement1\\_2.pdf](http://www.cdc.gov/nedss/BaseSystem/NEDSSBusinessDiscoveryStatement1_2.pdf)

Business Process Groups—documents, at a high level, the public health business processes that are within the scope of the NEDSS project. It documents what processes are targeted in the initial release of the system and which processes will be addressed in subsequent releases:

<http://www.cdc.gov/nedss/BaseSystem/BusinessProcessGroups.pdf>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention NEDSS Web site: <http://www.cdc.gov/nedss>



**For More Information**

Claire Broome, MD

Senior Advisor to the Director

Integrated Health Information Systems

Centers for Disease Control and Prevention

2960 Brandywine Road, Mailstop D68

Atlanta, GA 30341

E-mail: [cbroome@cdc.gov](mailto:cbroome@cdc.gov)

**Reviewed**

No





## National Vital Statistics System: Mortality (NVSS-M)

### Sector

Child and Family Services  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### Purpose

The National Vital Statistics System Mortality (NVSS-M) data set is generated from death certificate information collected through the National Vital Statistics System, an intergovernmental collaboration between NCHS and the 50 states, 2 cities, and 5 territories. The NVSS-M data serve as the primary source of information on demographic, geographic, and cause-of-death information among persons dying in a given year. Data are available on an annual basis.

### Version

Beginning with 1989, revised standard certificates replaced the 1978 versions; implementation of the next revision, for 2003, is being phased in by the states.

### Year Current Version Was Adopted

2003

### Age of Standard

The data system began in 1880, but not all states participated before 1933. Coverage for deaths has been complete since 1933.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

**Who Uses**

Administrative records (death certificates) completed by funeral directors, physicians, medical examiners, and coroners are filed with state vital statistics offices; selected statistical information is forwarded to NCHS to be merged into a national statistical file. Demographic information on the death certificate is provided by the funeral director and is based on information supplied by an informant. Medical certification of cause of death is provided by a physician, medical examiner, or coroner.

**Mandatory/Voluntary (and Authorization)**

Mandatory

**Estimate of Adoption**

NVSS mortality files include data for the 50 states, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Marianas. All deaths occurring in those areas are included (approximately 2.3 to 2.4 million annually).

**Standards Development Process**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for nationwide use through cooperative activities of the jurisdictions and NCHS.

**Type of Content**

Year of death, place of decedent's residence, place death occurred, age at death, day of week and month of death, Hispanic origin, race, marital status (beginning in 1979), place of birth, gender, underlying and multiple causes of death for all states, injury at work (beginning in 1993), hospital and patient status, and educational attainment (beginning in 1989) for selected states.

**Unit of Collection**

Individual

**Data Availability**

Public use data sets are available at no cost.

**Relationship to other Standards**

NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI); Medicare enrollment and claims data from the Centers for Medicare and Medicaid Services (CMS); and Retirement, Survivor, and Disability Insurance (RSDI) and Supplemental Security Income (SSI) benefit data from the Social Security Administration (SSA). See: [http://www.cdc.gov/nchs/r&d/nchs\\_data linkage/data\\_linkage\\_activities.htm](http://www.cdc.gov/nchs/r&d/nchs_data linkage/data_linkage_activities.htm)





Specifically for mortality, NCHS has developed a record linkage program designed to maximize the scientific value of the Center's population-based surveys. NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI). Linkage of the NCHS survey participants with the NDI provides the opportunity to conduct a vast array of outcome studies designed to investigate the association of a wide variety of health factors with mortality. NCHS surveys linked with mortality data:

- National Health Interview Survey (NHIS)
- NHANES I Epidemiologic Follow-up Study (NHEFS) Linked Mortality File
- Second National Health and Nutrition Examination Survey (NHANES II)
- Third National Health and Nutrition Examination Survey (NHANES III)
- The Second Longitudinal Study of Aging (LSOA II)
- 1985 National Nursing Home Survey

### **Future Plans**

CDC's National Center for Health Statistics is working with state partners represented by the National Association of Public Health Statistics and Information Systems and the Social Security Administration to fundamentally re-engineer the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates. The primary objective is to improve the timeliness, quality, and sustainability of the decentralized vital statistics system, along with collection of the revised and new content of the 2003 certificates, by adopting technologically sophisticated, yet cost-effective, model IT systems based on nationally developed standards and models. Information on the re-engineering activities and technical documents are available at the NAPHSIS Web site, as well as at the NCHS certificate revision Web site.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Latest Routine Reports and Associated Releases: <http://www.cdc.gov/nchs/deaths.htm>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics: <http://www.cdc.gov/nchs/nvss.htm>



**For More Information**

Edward J. Sondik, Ph.D.

Director

National Center for Health Statistics

3311 Toledo Road

Hyattsville, MD 20782

Telephone: (800) 232-4636

**Reviewed**

No





## National Vital Statistics System: Natality (NVSS-N)

### Sector

Child and Family Services  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### Purpose

The National Vital Statistics System Natality (NVSS-N) comprises records of all documented births occurring within the United States.

### Version

2003

### Year Current Version Was Adopted

2003

### Age of Standard

The national birth registration system was established in 1915. Not all states participated before 1933. Coverage for births has been complete since 1933.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics

### Who Uses

Administrative records (birth certificates) completed by physicians and midwives are filed with state vital statistics offices; selected statistical information is forwarded to NCHS to be merged into a national statistical file. Beginning with 1989, revised standard certificates replaced the 1978 versions; implementation of the next scheduled revision, for 2003, is being phased in by the states. Demographic information on the birth certificate is provided by the informant, usually the mother; maternal and infant health information is provided by the physician.



**Mandatory/Voluntary (and Authorization)**

In the United States, state laws require birth certificates to be completed for all births, and federal law mandates national collection and publication of births and other vital statistics data.

**Estimate of Adoption**

NVSS natality files include data for the 50 states, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Marianas. All births occurring in those areas are included (approximately 4 million annually).

**Standards Development Process**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the states and NCHS.

**Type of Content**

Demographic items collected include year of birth, place of mother's residence, place birth occurred, age of mother and of father, day of week and month of birth, Hispanic origin and race of mother and of father, marital status of mother, place of birth (for example, state or country) of mother and of father, educational attainment of mother and of father, sex of child, and live-birth order. Maternal and infant health information is collected, including month prenatal care began, number of prenatal visits, medical risk factors, tobacco use, alcohol use, maternal weight gain, obstetric procedures, attendant at birth, method of delivery, place of delivery, complications of labor and/or delivery, period of gestation, birthweight, Apgar score, abnormal conditions of newborn, congenital anomalies, and plurality.

**Unit of Collection**

Individual

**Data Availability**

Information on the Public Use Files and instructions for obtaining files can be located at [http://www.cdc.gov/nchs/products/elec\\_prods/subject/natality.htm](http://www.cdc.gov/nchs/products/elec_prods/subject/natality.htm), or by contacting [births@cdc.gov](mailto:births@cdc.gov).

**Relationship to other Standards**

NCHS is currently linking various NCHS surveys with death certificate records from the National Death Index (NDI); Medicare enrollment and claims data from the Centers for Medicare and Medicaid Services (CMS); and Retirement, Survivor, and Disability Insurance (RSDI) and Supplemental Security Income (SSI) benefit data from the Social Security Administration (SSA). See: [http://www.cdc.gov/nchs/r&d/nchs\\_data/linkage/data\\_linkage\\_activities.htm](http://www.cdc.gov/nchs/r&d/nchs_data/linkage/data_linkage_activities.htm)





### **Future Plans**

CDC's National Center for Health Statistics is working with state partners represented by the National Association of Public Health Statistics and Information Systems and the Social Security Administration to fundamentally re-engineer the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates. The primary objective is to improve the timeliness, quality, and sustainability of the decentralized vital statistics system, along with collection of the revised and new content of the 2003 certificates, by adopting technologically sophisticated, yet cost-effective, model IT systems based on nationally developed standards and models. Information on the re-engineering activities and technical documents are available at the NAPHSIS Web site, as well as at the NCHS certificate revision Web site.

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

Birth data: <http://www.cdc.gov/nchs/births.htm>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics: <http://www.cdc.gov/nchs/nvss.htm>

### **For More Information**

Edward J. Sondik, Ph.D.

Director

National Center for Health Statistics

3311 Toledo Road

Hyattsville, MD 20782

Telephone: (800) 232-4636

### **Reviewed**

No





## Pediatric Nutrition Surveillance System (PedNSS)

### Sector

Child and Family Services  
Food and Nutrition  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Purpose

The Pediatric Nutrition Surveillance System (PedNSS) is a child-based public health surveillance system that monitors the nutrition of low-income children in federally funded maternal and child health programs.

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

In the late 1960s, the United States Ten-State Nutrition Survey characterized the nutritional status of children from low-income families as being less than satisfactory. The findings generated concern about the nutritional status of low-income populations in the United States, especially children. Specifically, calories, calcium, iron, and vitamins A and C were less likely to be consumed in adequate amounts by low-income black and Hispanic children. In response, CDC began working with five states (Arizona, Kentucky, Louisiana, Tennessee, and Washington) in 1973 to develop a system for continuous monitoring of the nutritional status of selected high-risk population groups.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

**Who Uses**

Federally funded health clinics serving low-income children participate on a voluntary basis and report data to state-level agencies, which in turn submit data to CDC. The majority of PedNSS records (85.4 percent) are from the WIC Program. The figure below shows the distribution of records received from WIC, EPSDT, MCH, and other programs.

**Mandatory/Voluntary (and Authorization)**

PedNSS is a voluntary surveillance system. In 2007, 44 states, 1 U.S. Territory, 5 Indian Tribal Organizations, and the District of Columbia contributed data representing approximately 8 million children under 5 years of age.

**Estimate of Adoption**

In 2004, a total of 48 contributors, including 40 states, the District of Columbia, Puerto Rico, and 7 tribal governments, participated in PedNSS.

**Standards Development Process**

Unknown

**Type of Content**

Demographic data collected by PedNSS include race or ethnicity, sex, migrant status, household income (where indicated), and zip code. Data collected to assess nutritional status include weight, length/height, and hemoglobin or hematocrit measurements. Weight, stature, and length are commonly used to assess the size and growth of children. Data on birthweight and breastfeeding status are collected on children from birth to 2 years of age. Health risk behavior data includes tv/video viewing and household smoking.

**Unit of Collection**

Individual (unique child records)

**Data Availability**

National data set is not available to the public, but published tables and reports are available.

**Relationship to other Standards**

PedNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program; and
- Title V Maternal and Child Health Program (MCH).





A majority of the data are from the WIC program that serves children up to age 5.

An important use of the PedNSS data is monitoring the Healthy People 2010 objectives.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Unknown

### **Key Documents and Reports**

PedNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pednss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pednss_users_guide/index.htm)

2006 PedNSS Summary Report: [http://www.cdc.gov/pednss/pdfs/PedNSS\\_2006.pdf](http://www.cdc.gov/pednss/pdfs/PedNSS_2006.pdf)

National PedNSS data tables can be accessed through the following Web site:

<http://www.cdc.gov/pednss>

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):

<http://www.cdc.gov/pednss/index.htm>

### **For More Information**

Division of Nutrition, Physical Activity and Obesity

National Center for Chronic Disease Prevention and Health Promotion

Centers for Disease Control and Prevention

4770 Buford Highway NE

Mail Stop K-25

Atlanta, GA 30341-3717

Telephone: (770) 488-5702

### **Reviewed**

No





## Pregnancy Nutrition Surveillance System (PNSS)

### Sector

Child and Family Services  
Food and Nutrition  
Public Health

### Type of Standard

Reporting Requirements or Reporting Standards

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Purpose

The Pregnancy Nutrition Surveillance System (PNSS) monitors risk factors associated with infant mortality and poor birth outcomes among low-income pregnant women who participate in federally funded public health programs including Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); and Title V, the Maternal and Child Health Program (MCH).

### Version

Unknown

### Year Current Version Was Adopted

Unknown

### Age of Standard

PNSS has been in existence since 1979 when representatives from five states (Arizona, California, Kentucky, Louisiana, and Oregon) began working with CDC to develop a system for monitoring the prevalence of nutrition problems and behavioral risk factors related to mortality and low birthweight among infants born to high-risk pregnant women.

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)

### Who Uses

Federally funded health clinics serving pregnant women participate on a voluntary basis and report data to state-level agencies, which in turn submit the data to CDC. These data are combined for annual reporting. Approximately 99 percent of PNSS data comes from the WIC Program.





## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

In 2006, 26 states, 1 U.S. territory, and 5 Indian Tribal Organizations contributed data representing approximately 1.1 million women. The number of surveillance records has increased from approximately 10,000 in 1979 to over 700,000 in 2002.

## **Standards Development Process**

Unknown

## **Type of Content**

Data on maternal health indicators include pre-pregnancy weight status, maternal weight gain, parity, interpregnancy intervals, anemia, diabetes, and hypertension during pregnancy. Data on maternal behavioral indicators include medical care, WIC enrollment, multivitamin consumption, smoking, and drinking.

## **Unit of Collection**

Individual

## **Data Availability**

Data tables can be accessed through the following Web site:

[http://www.cdc.gov/pednss/pnss\\_tables/index.htm](http://www.cdc.gov/pednss/pnss_tables/index.htm)

## **Relationship to other Standards**

PNSS uses existing data from the following public health programs for nutrition surveillance:

- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC);
- Title V Maternal and Child Health Program (MCH)

A majority of the data are from the WIC program that serves pregnant, breastfeeding, and postpartum women.

An important use of the PNSS data is monitoring the Healthy People 2010 objectives.

## **Future Plans**

Unknown

## **Vendors Incorporating In Products**

Unknown





## **Key Documents and Reports**

PNSS User's Guide: [http://www.cdc.gov/pednss/additional\\_tools/pnss\\_users\\_guide/index.htm](http://www.cdc.gov/pednss/additional_tools/pnss_users_guide/index.htm)

## **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC):  
<http://www.cdc.gov/pednss/index.htm>

## **For More Information**

Division of Nutrition, Physical Activity and Obesity  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
4770 Buford Highway NE  
Mail Stop K-25  
Atlanta, GA 30341-3717  
Telephone: (770) 488-5702

## **Reviewed**

No





## Public Health Data Standards Consortium (PHDSC)

### Sector

Public Health

### Type of Standard

Standards Development Organization/Harmonization Effort

### Sponsor

Public Health Data Standards Consortium

### Purpose

The Public Health Data Standards Consortium (PHDSC) is committed to bringing a common voice from the public health community to the national efforts of standardization of health information technology and population health. PHDSC does not develop standards, but works with other standards development organizations to reflect the needs of public health.

### Version

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### Year Current Version Was Adopted

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### Age of Standard

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### Federal Involvement/Endorsement

Unknown

### Who Uses

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.



### **Mandatory/Voluntary (and Authorization)**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Estimate of Adoption**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Standards Development Process**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Type of Content**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Unit of Collection**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Data Availability**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

### **Relationship to other Standards**

The PHDSC has collaborated with the National Uniform Billing Committee (NUBC) representatives in the preparation of a Data Maintenance (DM) request to American National Standards Institute Accredited Standards Committee X12 (ANSI ASC X12), asking that ICD-10-CM (clinical modification) and ICD-10-PCS (procedure coding system) be added as sources for external cause of injury (codes) information. The October 2003 version (5010) of the ANSI ASC X12 837 implementation guides has been approved as a standard. These 5010 guides support the reporting of ICD-10-CM and ICD-10-PCS codes. Other highlights of the support provided in the 5010 version are additional slots to capture External Cause of Injury codes as well as slots to report Present on Admission Indicators associated with the Principal Diagnosis code, the Other Diagnoses codes, and the External Cause of Injury Codes.

The Public Health Data Standards Consortium has been invited by the Integrating the Healthcare Enterprise (IHE) to start a Public Health Domain at IHE. IHE is a collaborative of clinicians, administrators, standard development organizations, and health information technology (HIT) vendors that drives the adoption of





standards to address specific clinical needs through the development of the technical specifications for the software applications. PHDSC and IHE are collaborating to enable interoperability across clinical and public health enterprises.

PHDSC leadership participates in the CCHIT Privacy and Compliance Expert Panel and HITSP Board and HITSP Technical Committees.

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

PHDSC does not develop standards, but advocates for the inclusion of public health to other standards organizations.

Key Documents and Reports

A number of reports are located at: <http://www.phdsc.org/products/default.asp>

### **Web Site**

Public Health Data Standards Consortium Web site: <http://www.phdsc.org/default.asp>

### **For More Information**

Dr. Anna Orlova, Ph.D., Executive Director

Public Health Data Standards Consortium

624 N. Broadway, Room 382

Baltimore MD 21205

Telephone: (410) 614-3463

Facsimile: (410) 614-3097

E-mail: [aorlova@jhsphe.edu](mailto:aorlova@jhsphe.edu)

### **Reviewed**

No





## Public Health Information Network (PHIN)

### Sector

Public Health

### Type of Standard

Data Interoperability Standard

### Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Purpose

The Public Health Information Network (PHIN) is a national initiative to improve the capacity of public health to use and exchange information electronically by promoting the use of standards, defining functional and technical requirements.

PHIN strives to improve public health by enhancing research and practice through best practices related to efficient, effective, and interoperable public health information systems. PHIN Certification certifies the ability of an application (or multiple applications, components, or systems) to perform specific functions in compliance with the PHIN Requirements and Certification Criteria. The criteria for certification, the PHIN Certification details, and a general description of the PHIN Certification process are available in PHIN Certification Criteria and Process v1.0 document.

### Version

PHIN Requirements Version 2.0

### Year Current Version Was Adopted

2007

### Age of Standard

2005

### Federal Involvement/Endorsement

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention

### Who Uses

Public health agencies at all levels of government





## **Mandatory/Voluntary (and Authorization)**

Voluntary

## **Estimate of Adoption**

Unknown

## **Standards Development Process**

CDC collaboratively develops requirements for public health information systems to ensure that they are able to electronically exchange data between systems and across jurisdictions. To ensure that PHIN requirements are beneficial and effective for all partners, the CDC PHIN Requirements team:

- Openly and transparently engages and collaborates with CDC internal and external partners to create an interoperable public health information network to permit effective and efficient electronic information sharing between partners during events or conditions of a public health importance.
- Develops, based on partner input, PHIN Requirements to:
  - ♦ emphasize the use of electronic information systems to exchange, communicate, and protect data,
  - ♦ describe recommendations that support interoperable information systems implementation,
  - ♦ describe how information systems support typical public health activities,
  - ♦ provide supplemental information that may assist in implementing interoperable information systems, including applicable standards, guidelines, examples, best practices, and potential promising practices.
- Integrates applications that support PHIN by identifying and applying best practices (successful systems and or processes) from external and internal partners.

## **Type of Content**

Requirements for PHIN compliance are limited to interoperability for information systems. However, additional recommendations are provided in recognition that there are many other activities that must be performed before attaining this level of capability.

## **Unit of Collection**

Unknown

## **Data Availability**

Unknown





### **Relationship to other Standards**

PHIN uses a number of other standards including (but not limited to): HL7 messaging standards, Emergency Data Exchange Language (EDXL) V 1.0 Distribution Element EDXL, Common Alerting Protocol (CAP) V 1.1

### **Future Plans**

Unknown

### **Vendors Incorporating In Products**

Yes

### **Key Documents and Reports**

PHIN Requirements 2.0: <http://www.cdc.gov/phn/library/documents/pdf/PHIN%20requirements%20V2.0.pdf>

PHIN Certification Criteria and Process v1.0 document: [http://www.cdc.gov/phn/library/documents/pdf/PHIN\\_Cert\\_Criteria\\_Process-v1.0.pdf](http://www.cdc.gov/phn/library/documents/pdf/PHIN_Cert_Criteria_Process-v1.0.pdf)

### **Web Site**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, PHIN Web site: <http://www.cdc.gov/PHIN>

### **For More Information**

Terry Boyd

Acting Director

CDC/NCPHI/Division of Applied Informatics Services (DAIS, proposed)

Centers for Disease Control and Prevention

1600 Clifton Road

Atlanta, GA 30333

Telephone: (404) 639-3311

E-mail: [ttb9@cdc.gov](mailto:ttb9@cdc.gov)

### **Reviewed**

No



# APPENDIX A

## BEYOND STANDARDS: OTHER CHALLENGES TO DATA SHARING

Solving the problem of communicating between standards in data sharing is not trivial. Indeed, standards reconciliation is a necessary component in information sharing. But standards reconciliation alone is not sufficient, in ensuring a data sharing strategy. A number of non-standards related challenges must also be solved. Although a full description of these challenges is beyond the scope of this catalog, a summary of some of the most important non-standards related issues is discussed below:

1. **Privacy and Confidentiality of Client Information** – entities that share information must have dependable ways to ensure privacy and confidentiality. Additionally, many possible sharing partners must comply with federal and state laws because of the particular nature of the information that they maintain.
  - i. HIPAA's Administrative Simplification establishes requirements in four areas: electronic transactions and code sets, privacy, security, and national identifiers. HIPAA applies to health information that is created or received by a healthcare provider, health plan, public health authority, employer, life insurer, school or university, or healthcare clearinghouse; and relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual.
  - ii. 42 C.F.R establishes federal rules for protecting individually identifiable information that is maintained through a federally assisted drug abuse program or by medical professionals who provide drug and alcohol abuse diagnosis, treatment, or referral. State laws may incorporate "nonfederally assisted" programs under this rule, as well. Protected information, in general, may not be disclosed without written patient consent.
  - iii. Violence Against Women Act (1994) and its reauthorization (2006) include important privacy provisions including protection of the confidentiality and privacy of victims of domestic violence who receive services.
  - iv. Many states have laws that place additional restrictions on privacy and security of health information that involves mental health and substance abuse, HIV-AIDS or sexually transmitted diseases, or other conditions.
2. **Information Technological Infrastructure** - it is widely known that human service organizations, particularly community-based organizations, lag behind in the adoption of information technology. Even with emerging standards, information sharing is not easy. In most cases, information technology expertise (hardware and software) is required to implement and maintain ongoing sharing. Small organizations may not have the funding or knowledge to identify professionals who may help them. There are at least four major areas that should be addressed in reviewing technological infrastructures:

# Appendix A

Understanding Human Services Utilization: October 2009

- i. **Network Communications** – in the not-so-distant past, organizations were unable to quickly or inexpensively share information without huge investments in laying fiber. Today, the Internet can be a secure way to share information quickly. Internet availability continues to be more widespread. In many ways, the Internet's ubiquity answers one of the vexing communication problems that faced those wanting to share information less than a generation ago.
- ii. **Hardware and Software** – in order for nonprofits to use systems for client information, the systems must be readily accessible, user-friendly, fit within workflows, and be supported. Many information technology implementations fail without these components. Additionally, incompatibilities in hardware and software may cause difficulties in sharing data. Organizations may be using antiquated hardware and software that cannot easily be modified for information sharing. Depending on the type of architecture being employed to enable data sharing, additional hardware (for example, servers, switches, firewalls) may be needed.

**3. Data Quality and Content** - there are two aspects to the actual content of the data that are important to consider: data meaning and data quality. Data meaning refers to what the information is supposed to represent to users. Standards help smooth the path to understandable data meaning, but they rarely definitively ensure that data are maintained in exactly the same way or mean exactly the same thing in different implementations. Standards may be fairly broad, allowing great discretion in how an organization uses aspects of it, or may be extremely precise. Obviously, the greater the precision, the easier it is to know exactly what the information means, but it also provides less flexibility. Before sharing data, it is important to understand the quality of the data partners are sharing. That is, does the data represent all clients; are records complete and up-to-date? Or, does it only represent clients of certain case managers, or represent only the clients the receptionist has had time to enter into the system? Are there quality checks and how are inconsistencies reconciled? What established and regular systems of communication will be established to improve the sharing system?

**4. Client matching strategies** – a crucial aspect to sharing information is being able to confidently identify what information relates to what client. Names, alone, are insufficient identifiers for data matching. Often several unique identifiers are used to link data concerning people, programs, or plans from different databases. The Homeless Management Information System Integration Strategies and Solutions report (<http://www.hmis.info/ClassicAsp/documents/HMIS%20Data%20Integration%202003.pdf>) ably describes client matching approaches that HMIS systems might consider, including those when clients are fully identified, assigned client codes, or matched through cryptographic solutions. A health information exchange initiative in Massachusetts, MA-SHARE ([http://www.mahealthdata.org/ma-share/projects/communitympi/20040416\\_UPIpaper.pdf](http://www.mahealthdata.org/ma-share/projects/communitympi/20040416_UPIpaper.pdf)), has developed an excellent resource guide comparing client matching strategies, including:



- i. **Deterministic** – this is the simplest because in order for a provider to get a client match, all the information must be exactly as the provider inputted it.
- ii. **Probabilistic** – this approach creates customized weights for each of the demographic identifiers. Instead of requiring an exact match, slight variations are allowed for (and highlighted). For example, information for a client who has a close, but not exact, date of birth (it may not be exact because of a number transposition) may also be offered to the provider. The results are often given back to the provider via a scoring system, so that the provider can see how similar or different the client's demographic information is. This probabilistic approach is supported by sophisticated algorithms and statistical methods that require fairly high-powered and sophisticated computing systems.
- iii. **Fuzzy Matching** – this is a “middle ground,” that uses a combination of deterministic and probabilistic methods. It requires less computing power, since the probabilistic approach does not apply to all client demographic information.

**5. Technological Expertise** – is often needed to achieve and maintain data sharing. Experts in software, programming, and hardware may be needed. Developing the technological systems for data exchange may require numerous decisions by the agencies attempting to share data. Agencies should select IT professionals who know, or are willing to learn, about human services agencies and the challenges they face. Vital questions that IT professionals along with agencies should decide are: Will data be stored in a central data repository or maintained by each agency? Must data be simultaneously updated (always current) or periodically updated (for example, hourly, daily, weekly)? Will information be synchronized or overwritten? Will certain information sources be privileged over others? How will changes in standards impact data sharing? What ongoing maintenance needs and supports are there?

**6. Cost** – perhaps the most challenging barrier to client information exchange is cost. Many human service organizations have difficulty identifying funding for what is seen as an administrative expense. Other organizations may find it difficult to justify IT expenditures when funds could be used to help clients.



## APPENDIX B

### STANDARDS CONSIDERED BUT ULTIMATELY DID NOT MEET INCLUSION CRITERIA FOR CATALOG

**AIRS/211 LA Taxonomy of Human Services** – is the most widely used taxonomy for human services in North America. The taxonomy comprises approximately 10,000 terms, organized into 11 categories: basic needs, consumer services, criminal justice and legal services, education, environmental quality, health care, income support and employment, individual and family life, mental health care and counseling, organizational/community/international services, and target populations.

<http://www.211taxonomy.org>

**American Community Survey (ACS)** – a nationwide survey that is intended to eliminate the long form in the 2010 Census. ACS collects information from U.S. households including income, commute time to work, home value, veteran status, and so on. Persons living in group quarters are NOT included in the sample.

<http://www.census.gov/acs/www>

**American National Standards Institute (ANSI)** – coordinates the development and use of voluntary consensus standards, but does not itself develop standards. ANSI provides the framework of rules and accreditation of standards that standards development organizations maintain. The Institute ensures that access to the standards process is made available to anyone directly or materially affected by a standard under development. <http://www.ansi.org>

**American Society for Testing and Materials (ASTM)** - one of the largest voluntary standards development organizations in the world. ASTM develops technical standards for materials, products, systems, and services. The ASTM Committee E31 on Healthcare Informatics develops standards related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within health care and healthcare decisionmaking, including patient-specific information and knowledge. <http://www.astm.org>

**Behavioral Risk Factor Surveillance System (BRFSS)** – designed to collect state-specific general population data on behaviors that are related to the leading causes of morbidity and mortality. BRFSS is administered through a telephone surveillance system with data collected each month throughout the calendar year in all 50 states, District of Columbia, Puerto Rico, Virgin Islands, and Guam.

<http://www.cdc.gov/BRFSS>



# Appendix B

Understanding Human Services Utilization: October 2009

**Child and Family Services Reviews (CFSR)** - designed to enable the U.S. HHS Children's Bureau to ensure that state child welfare agency practice is in conformity with federal child welfare requirements, to determine what is actually happening to children and families as they are engaged in state child welfare services, and to assist states to enhance their capacity to help children and families achieve positive outcomes.

<http://www.nrccwdt.org/resources/cfsr/cfsr.html>

**Child Welfare Extensible Markup Language (CW XML)** – APPARENTLY DEFUNCT - had been a part of the National Resource Center for Child Welfare Data and Technology. The goal had been standards to enable transport and translation through secure channels across geographical and organizational boundaries to enable the delivery and management of quality services that can assist children and their families.

<http://www.nrccwdt.org/xml/intro.html>

**Client/Patient Sample Survey (CPSS)** - creates national estimates and sociodemographic, clinical, and services use characteristics of persons who receive services in specialty mental health organizations nationwide. The survey is fielded intermittently. CPSS is sponsored by SAMHSA and the Center for Mental Health Services, collected by the Center for Mental Health Services.

**Clinical Care Classification System (CCC)** - a classification system consisting of two interrelated taxonomies: the CCC of Nursing Diagnoses and Outcomes, and the CCC of Nursing Interventions and Actions. Both taxonomies are classified by care components, or clusters of elements that represent behavioral, functional, physiological, or psychological care patterns.

<http://www.sabacare.com>

**Clinical Data Interchange Standards Consortium (CDISC)** - CDISC is a global, open, multidisciplinary, nonprofit organization that has established standards to support the acquisition, exchange, submission, and archive of clinical research data and metadata. The CDISC mission is to develop and support global, platform-independent data standards that enable information system interoperability to improve medical research and related areas of health care. CDISC standards are vendor-neutral, platform-independent, and freely available via the CDISC Web site.

<http://www.cdisc.org/index.html>

**Commission on Systematic Interoperability (CSI)** – was charged in 2005 to develop a comprehensive strategy for the adoption and implementation of healthcare information technology standards. Section 1012 of the Medicare Modernization Act required the Secretary of HHS to establish the Commission on Systemic Operability. CSI's work was concluded in 2005.

[www.os.dhhs.gov/healthit/commission.html](http://www.os.dhhs.gov/healthit/commission.html)



**Common Alerting Protocol (CAP)** - a simple but general format for exchanging all-hazard emergency alerts and public warnings over all kinds of networks. CAP allows a consistent warning message to be disseminated simultaneously over many different warning systems, thus increasing warning effectiveness while simplifying the warning task. CAP also facilitates the detection of emerging patterns in local warnings of various kinds, such as might indicate an undetected hazard or hostile act. CAP was adopted in 2004 by the OASIS standards development organization and is being implemented in numerous federal, state, and local information systems.

It was sponsored by the Partnership for Public Warning, the Emergency Interoperability Consortium, the ComCARE Alliance, and the Disaster Management e-Gov Initiative.

<http://www.oasis-open.org/apps/org/workgroup/emergency/download.php/14205/emergency-CAPv1.1-Committee%20Specification.pdf>

**Common Core of Data (CCD)** - a program of the U.S. Department of Education's National Center for Education Statistics that annually collects fiscal and non-fiscal data about all public schools, public school districts, and state education agencies in the United States. The data are supplied by state education agency officials and include information that describes schools and school districts including name, address, and telephone number; descriptive information about students and staff, including demographics; and fiscal data, including revenues and current expenditures.

<http://nces.ed.gov/ccd>

**Current Dental Terminology (CDT)** - a coding system developed to report services performed by the dental profession. CDP was developed by the American Dental Association and was formerly called the Uniform Code on Dental Procedures and Nomenclature.

<http://www.ada.org/ada/prod/catalog/cdt/index.asp>

**Current Procedural Terminology (CPT)** - a private classification system maintained and licensed by the American Medical Association. CPT is a comprehensive list of descriptive terms and codes used for reporting diagnostic and therapeutic procedures and other medical services performed by physicians. These codes are used for the billing of medical procedures.

<http://www.ama-assn.org/ama/pub/category/3113.html>

**Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)** - a nomenclature to standardize the diagnostic process for patients with psychiatric disorders. <http://www.appi.org/dsm.cfx>

**Disaster Management eGov Initiative (DM)** - was one of 24 eGov initiatives established by President Bush's Management Agenda to support a multitude of federal agency missions including the U.S. Department of Homeland Security and FEMA to reduce the loss of life and property in any phase of a disaster event. DM has been split into two government efforts: 1) DHS Science and Technology directorate facilitates the EDXL practitioner and SDO processes in the development of EDXL standards; and 2) FEMA is now responsible for

# Appendix B

Understanding Human Services Utilization: October 2009

implementation assistance of EDXL standards through an SOA architecture called OPEN (Open Platform for Emergency Networks).  
[www.disasterhelp.gov](http://www.disasterhelp.gov)

**Digital Imaging and Communications in Medicine (DICOM)** - messaging standard for the transmission of digital images. The standard enables images and related diagnostic information to be sent and received from various manufacturers' products as well as medical workstations. This standard was developed by the joint committee of the American College of Radiology and the National Electrical Manufacturers Association to meet the needs of manufacturers and users of medical imaging equipment for interconnection of devices on standard networks.

<http://medical.nema.org/dicom/>

**Drug Abuse Warning Network (DAWN)** - captures data about drug-related emergency department visits and drug-related deaths from a stratified geographic sample. DAWN is an ongoing, national public health surveillance system that collects data and reports information on adverse health consequences associated with drug misuse and abuse through drug-related emergency department visits and medical examiners and coroners.

DAWN is sponsored by SAMHSA and the Office of Applied Studies.

<http://dawninfo.samhsa.gov>

**ESIGN law** – defines signature standards for all prescriptions allowing e-signatures.

**Food and Nutrition Service Program Operations Data** - statistical information on aspects of all major Food and Nutrition Service (FNS) food and nutrition assistance programs. These programs include the Food Stamp Program; the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); Child Nutrition Programs (National School Lunch, School Breakfast, Child and Adult Care, Summer Food Service, and Special Milk); and Food Distribution Programs (Schools, Emergency Food Assistance, Indian Reservations, Commodity Supplemental, Nutrition for the Elderly, and Charitable Institutions). Four types of tables are provided: historical summaries, annual state-level data for selected elements, monthly national-level data for major programs, and state-level participation in major programs for the latest available month.

<http://www.ers.usda.gov/Briefing/FoodNutritionAssistance/data>

**Food Stamp Program Quality Control Database (FSPQC)** - contains detailed demographic, economic, and Food Stamp Program eligibility information for a nationally representative sample of approximately 50,000 participating households.

**Global Medical Device Nomenclature (GMDN)** - a collection of internationally recognized terms used to describe and catalog medical devices, in particular, products used in the diagnosis, prevention, monitoring, treatment, or alleviation of disease or injury in humans.

[www.gmdn.org/index.xalter](http://www.gmdn.org/index.xalter)



**Health Industry Business Communications Council (HIBCC)** - an ANSI business-to-business standards development organization enables electronic communication through standards for electronic data interchange message formats, bar code labeling data, universal numbering systems, and the provision of databases which assure common identifiers. Current major standards include:

- Standardized manufacturer, customer, and product identification codes, including the Labeler Identification Code (LIC), Health Industry Number (HIN®), Universal Product Number (UPN®), and the Health Industry Bar Code (HIBC) Standards
- Computerized EDI protocols in ASC X12 approved message formats  
<http://www.hibcc.org/index.htm>

**Healthcare Cost and Utilization Project (HCUP)** – a family of healthcare databases and tools sponsored by U.S. HHS Agency for Healthcare Research and Quality. The following files are distributed through the HCUP Central Distributor:

- Nationwide Inpatient Sample (NIS) ([www.hcup-us.ahrq.gov/nisoverview.jsp](http://www.hcup-us.ahrq.gov/nisoverview.jsp)) – database of hospital inpatient stays.
- Kids Inpatient Database (KID) ([www.hcup-us.ahrq.gov/kidoverview.jsp](http://www.hcup-us.ahrq.gov/kidoverview.jsp)) – sample of pediatric inpatient discharges.
- State Inpatient Databases (SID) - ([www.hcup-us.ahrq.gov/sidoverview.jsp](http://www.hcup-us.ahrq.gov/sidoverview.jsp)) – inpatient discharge abstracts.
- State Ambulatory Surgery Databases (SASD) ([www.hcup-us.ahrq.gov/sasdooverview.jsp](http://www.hcup-us.ahrq.gov/sasdooverview.jsp)) – ambulatory care encounters from hospital-affiliated and sometimes freestanding ambulatory surgery sites.
- State Emergency Department Databases (SEDD) ([www.hcup-us.ahrq.gov/seddooverview.jsp](http://www.hcup-us.ahrq.gov/seddooverview.jsp)) – data from hospital-affiliated emergency departments for visits that do not result in hospitalizations

<http://www.ahrq.gov/data/hcup>

**Healthcare Information and Management Systems Society (HIMSS)** - a membership organization focused on providing global leadership for the optimal use of healthcare information technology and management systems for the betterment of health care.

<http://www.himss.org>

**HIPAA Privacy Standard/Rule** - its protections extend to every patient whose information is collected, used, or disclosed by covered entities. It imposes responsibilities on the entire workforce of a covered entity—including all employees and volunteers—in order to secure those rights. It also requires contractual assurances for any business associates of healthcare institutions that handle healthcare information on a covered entity's behalf.

<http://www.hipaa.org>

# Appendix A

Understanding Human Services Utilization: October 2009

**HIPAA Security Standards** - specifies a series of administrative, technical, and physical security procedures for covered entities to use to assure the confidentiality of electronic protected health information. The standards are delineated into either required or addressable implementation specifications.

<http://www.hipaa.org>

**HIPAA Transaction and Code Sets Standards** – covers transactions: activities involving the transfer of healthcare information for specific purposes. HIPAA requires every provider who does business electronically to use the same healthcare transactions, code sets, and identifiers. HIPAA has identified 10 standard transactions for Electronic Data Interchange (EDI) for the transmission of healthcare data. Claims and encounter information, payment and remittance advice, and claims status and inquiry are several of the standard transactions. Code sets are the codes used to identify specific diagnosis and clinical procedures on claims and encounter forms.

<http://www.hipaa.org>

**International Classification of Diseases, Ninth Edition, Clinical Modifications (ICD-9/ICD-10)** – is the U.S. government's expansion of the World Health Organization's International Classification of Disease (ICD) coding system. The standards are controlled by the federal government via the National Center for Health Statistics (NCHS) and the Centers for Medicare and Medicaid Services (CMS). U.S. HHS has mandated adoption of ICD-10 transaction standards, by 2013, to replace the 30-year-old ICD-9 codes currently used for recording medical diagnoses and billing for treatments.

**IEEE 1073** – a family of medical device communications standards which allows hospitals and other healthcare providers to achieve plug-and-play interoperability between medical instrumentation and computerized healthcare information systems, especially in a manner that is compatible with the acute care environment. It is sponsored by the Institute of Electrical and Electronics Engineers, Inc. <http://standards.ieee.org/resources/index.html>

**International Classification of Functioning, Disability and Health (ICF)** - a health and health-related classification system that reports body functions and structures, activities, and participation.

[www3.who.int/icf/icftemplate.cfm?myurl=homepage.html&mytitle= Home%20Page](http://www3.who.int/icf/icftemplate.cfm?myurl=homepage.html&mytitle=Home%20Page)

**International Classification of Primary Care (ICPC)** - a classification system for primary care physicians that enables the labeling of the most prevalent conditions that exist in the community as well as symptoms and complaints.

<http://www.globalfamilydoctor.com/wicc/sensi.html>

**Institute of Medicine Committee on Patient Safety Data Standards** – charged with producing a detailed plan to facilitate the development of data standards applicable to the collection, coding, and classification of patient safety information.

[www.iom.edu/psds](http://www.iom.edu/psds)



## **LegalXML** – standards for the legal profession including

- LegalXML eContracts – data interoperability standards for the markup of contract documents to enable the efficient creation, maintenance, management, exchange, and publication of contract documents and contract terms.
  - LegalXML Electronic Court Filing – a data interoperability standard to create legal documents and to transmit legal documents from an attorney, party or self-represented litigant to a court; from a court to an attorney, party or self-represented litigant or to another court; and from an attorney or other user to another attorney or other user of legal documents.
  - LegalXML eNotary – a set of technical requirements to govern self-proving electronic legal information.
  - LegalXML Integrated Justice - XML standards for exchanging data among justice system branches and agencies.
  - LegalXML Legislative Documents - XML standards for the markup of legislative documents and a system of simple citation capability for non-legislative documents (for example, newspaper articles).
  - LegalXML Legal Transcripts - XML standards for the syntax to represent legal transcript documents either as stand-alone structured content or as part of other legal records.
  - LegalXML Online Dispute Resolution (OdrXML) - XML standards for the markup of information and documents used in online dispute resolution systems.
  - LegalXML Subscriber Data Handover Interface (SDHI) - XML standards for the production of consistent Subscriber Data Handover Interface (SDHI), by telecommunication or Internet service providers, concerning a subscriber or communications identifier (for example, a telephone number) in response to an XML structured request which includes, when necessary, authorization from a judicial, public safety, or law enforcement authority.
- <http://www.legalxml.org>

**LOINC (Logical Observation Identifiers, Names and Codes)** - a data vocabulary standard for names and codes for laboratory tests results and other observations developed by Regenstrief Institute. LOINC codes are used as universal identifiers for laboratory and other clinical translations that facilitate the exchange and pooling of results, such as blood hemoglobin, serum potassium, or vital signs for clinical care, outcomes management, and research.

<http://www.loinc.org> [www.loinc.org](http://www.loinc.org).

**MEDCIN** - a terminology and presentation engine that includes more than 250,000 clinical data elements encompassing symptoms, history, physical examination, tests, diagnoses, and therapy.

<http://www.medicomp.com>

# Appendix B

Understanding Human Services Utilization: October 2009

**National Ambulatory Medical Care Survey (NAMCS)** – sponsored by the National Center for Health Statistics and collected by the U.S. Census Bureau. The survey has data on utilization and provision of medical care services at visits to approximately 3,000 office-based physicians.

<http://www.cdc.gov/nchs/about/major/ahcd/namcsdes.htm>

**National and State Data on Substance Abuse Treatment Facilities (N-SSATS)** – an annual census of facilities providing substance abuse treatment. This survey is designed to collect data on the location, characteristics, and use of alcoholism and drug abuse treatment facilities and services throughout the 50 states, the District of Columbia, and other U.S. jurisdictions.

<http://www.oas.samhsa.gov/DASIS/2k6nssats.cfm>

**National Cancer Institute Cancer Biomedical Informatics Grid (caBIG)** - a voluntary network or grid connecting individuals and institutions to enable the sharing of data and tools, creating a World Wide Web of cancer research.

<https://cabig.nci.nih.gov>

**National Center for Health Statistics (NCHS)** - provides statistical information to guide actions and policies to improve the health of the American people. NCHS is the nation's principal health statistics agency and has two major types of data systems: systems based on populations, containing data collected through personal interviews or examinations; and systems based on records, containing data collected from vital and medical records:

- National Health Interview Survey
  - ♦ National Health Interview Survey on Disability
- National Health and Nutrition Examination Survey
  - ♦ NHANES I Epidemiologic Followup Study
    - National Health Care Survey
- ♦ Ambulatory Health Care Data (NAMCS/NHAMCS)
- ♦ Hospital Discharge and Ambulatory Surgery Data
  - ♦ National Home and Hospice Care Survey
    - ♦ National Nursing Home Survey
- ♦ National Employer Health Insurance Survey
  - National Vital Statistics System
    - ♦ Birth Data
    - ♦ Mortality Data
    - ♦ Fetal Death Data
    - ♦ Linked Births/Infant Deaths
- ♦ National Mortality Followback Survey
- ♦ National Maternal and Infant Health Survey





- ♦ Vital Statistics Data Available Online
  - National Survey of Family Growth
  - National Immunization Survey
- The Longitudinal Studies of Aging (LSOAs)
- State and Local Area Integrated Telephone Survey
- Joint Canada/United States Survey of Health (JCUSH)  
<http://www.cdc.gov/nchs/Default.htm>

**National Center for State Courts Technology Standards** - defines functional requirements for in-house systems development and requests for proposals for vendor-supplied computer systems.  
[http://www.ncsconline.org/d\\_tech/standards/default.asp](http://www.ncsconline.org/d_tech/standards/default.asp)

**National Council for Prescription Drug Programs (NCPDP) Batch Transaction Standard** - provides practical guidelines and ensures consistent implementation throughout the industry of a file submission standard to be used between pharmacies and processors, or pharmacies, switches, and processors. <http://www.ncdp.org>

**National Drug Code (NDC)** – is a coding system for pharmacies to report services, supplies, drugs, and biologic information. NDC was developed by pharmaceutical manufacturers and maintained by the FDA.  
[www.fda.gov/cder/ndc/index.htm](http://www.fda.gov/cder/ndc/index.htm)

**National Health and Nutrition Examination Survey (NHANES)** – assesses health and nutritional status of the U.S. noninstitutionalized civilian population through direct physical examinations, laboratory tests, and interviews. NHANES is sponsored by the National Center for Health Statistics and collected by Westat.  
<http://www.cdc.gov/nchs/nhanes.htm>

**National Hospital Ambulatory Medical Care Survey (NHAMCS)** – collects data on the utilization and provision of medical care services in hospital emergency and outpatient departments. It is sponsored by the National Center for Health Statistics and collected by the U.S. Census Bureau.  
<http://www.cdc.gov/nchs/about/major/ahcd/nhamcsds.htm>

**National Health Interview Survey (NHIS)** – the principal source of information on the health of the population of the United States. Data collected through personal household interview surveys conducted by trained interviewers. NHIS is sponsored by the National Center for Health Statistics and collected by the U.S. Census Bureau.  
<http://www.cdc.gov/nchs/nhis.htm>



# Appendix B

Understanding Human Services Utilization: October 2009

**National Hospital Discharge Survey (NHDS)** - collects and produces national estimates on characteristics of inpatient stays in non-federal hospitals. NHDS is sponsored by the National Center for Health Statistics and collected by the U.S. Census Bureau.

<http://www.cdc.gov/nchs/about/major/hdasd/nhds.htm>

**National Mortality Followback Survey (NMFS)** – provides information on mortality beyond that routinely collected on the death certificate. NMFS is sponsored by the National Center for Health Statistics and collected by the U.S. Census Bureau.

<http://www.cdc.gov/nchs/about/major/nmfs/nmfs.htm>

**National Nursing Home Survey (NNHS)** - provides information on characteristics of nursing homes and their residents. Sponsored by the National Center for Health Statistics and collected by Westat.

<http://www.cdc.gov/nchs/nnhs.htm>

**National Nursing Home Survey Followup (NNHSF)** - provides data on the flow of persons in and out of long-term care facilities and hospitals. NNHSF is sponsored by the National Center for Health Statistics and collected by Research Triangle Institute.

[http://www.cdc.gov/nchs/products/elec\\_prods/subject/nnhsf.htm](http://www.cdc.gov/nchs/products/elec_prods/subject/nnhsf.htm)

**National Provider Identifier (NPI)** - required for, among others, healthcare providers conducting HIPAA standard transactions.

<http://www.cms.hhs.gov/NationalProvIdentstand>

**National Quality Forum (NQF)** - a not-for-profit membership organization created to develop and implement a national strategy for healthcare quality measurement and reporting. Its mission is to improve the quality of American health care by setting national priorities and goals for performance improvement, endorsing national consensus standards for measuring and publicly reporting on performance, and promoting the attainment of national goals through education and outreach programs. <http://www.qualityforum.org>

**National Resource for Global Standards** - a search engine that provides users with standards-related information from a wide range of developers, including organizations accredited by the American National Standards Institute (ANSI), other U.S. private sector standards bodies, government agencies, and international organizations.

<http://www.nssn.org>

**National Survey of Veterans (NSV)** – describes characteristics of the veteran population. Sponsored by Office of Program and Data Analyses, Department of Veterans Affairs, and conducted last in 2001.

<http://www1.va.gov/vetdata/page.cfm?pg=5>



**National Survey on Drug Use and Health (NSDUH)** - the primary source of information on the prevalence and incidence of illicit drug, alcohol, and tobacco use. Information about substance abuse and dependence, mental health programs, and receipt of substance abuse and mental health treatment also is included. Persons excluded from the survey include homeless people who do not use shelters. NSDUH is sponsored by SAMHSA and the Office of Applied Studies, and collected by Office of Applied Studies.

<https://nsduhweb.rti.org>

**National Vital Statistics System: Linked Birth-Infant Death (NVSS-I)** – links vital statistics data sets.

<http://www.cdc.gov/nchs/nvss.htm>

**National Institute on Standards and Technology (NIST)** - an agency of the Department of Commerce that creates many of the federal government's security standards, which are mandated for use in government agencies and often by their contractors. Formerly known as the Bureau of Standards.

<http://www.nist.gov>

**New Beneficiary Data System (NBDS)** – a longitudinal survey of aged and disabled Social Security beneficiaries, administered in 1982 and 1991. <http://www.ssa.gov/policy/docs/microdata/nbds/index.html>

**North American Nursing Diagnosis Association (NANDA) International Taxonomy II** - a conceptual system that guides the classification of nursing diagnoses.

[www.nanda.org/html/taxonomy.html](http://www.nanda.org/html/taxonomy.html)

**Nursing Interventions Classification (NIC)** - a standardized classification of interventions that nurses perform.

[www.nursing.uiowa.edu/centers/cncce/nic](http://www.nursing.uiowa.edu/centers/cncce/nic)

**Nursing Outcomes Classification (NOC)** - a classification of patient/client outcomes developed to evaluate the effects of nursing interventions.

<http://www.nursing.uiowa.edu/centers/cncce/noc>

**Omaha System** - a taxonomy designed to generate meaningful data following usual or routine documentation of client care.

<http://www.omahasystem.org>

**Organization for the Advancement of Structured Information Standards (OASIS)** – a not-for profit consortium that drives the development, convergence, and adoption of open standards for the global information society. OASIS “hosts” a number of the standards listed in this catalog.

<http://www.oasis-open.org/home/index.php>

# Appendix B

Understanding Human Services Utilization: October 2009

**Pregnancy Risk Assessment Monitoring System (PRAMS)** - a monthly random sample of women (approximately 1,300–3,400 women per state) who have delivered a live-born infant during the preceding 2–4 months.

<http://www.cdc.gov/prams>

**Regional Alliances for Infrastructure and Network Security (RAINS)** - a nonprofit, private/public partnership formed to accelerate development and deployment of innovative technology for homeland security.

<http://www.aboutus.org/Wiki>

**RxNorm** – is a normalized notation for clinical drugs. RxNorm was developed as a joint project between the national Library of Medicine and the Veterans Health Administration.

<http://www.nlm.nih.gov/research/umls/rxnorm>

**Standards.gov** - supports the requirements of the National Technology Transfer and Advancement Act (NTTAA), which became law in 1996. The NTTAA directs federal agencies with respect to their use of private sector standards and conformity assessment practices. The objective is for federal agencies to adopt private sector standards, wherever possible, in lieu of creating proprietary, nonconsensus standards. Standards.gov is maintained and operated by the National Institute of Standards and Technology (NIST).

[http://standards.gov/standards\\_gov/v/Standards/index.cfm](http://standards.gov/standards_gov/v/Standards/index.cfm)

**Survey of Veteran Enrollees' Health and Reliance Upon the Veterans Administration** - surveys of veteran enrollees for VA health care sponsored by the Office of the Assistant Deputy Under Secretary for Health for Policy and Planning, Department of Veteran Affairs. Data were last collected in 2005.

**State Court Guide to Statistical Reporting** - model approach for counting, defining, and classifying cases at both the filing and resolution stages, and provides a framework for developing a more accurate picture of court caseloads and workloads for trial and appellate courts, as well as state court administrators. In addition, the Guide supports the ongoing development of court case management and information systems by clarifying the definition, scope, and interrelationship of critical data elements.

<http://www.ncsconline.org>

**Strategy Markup Language (StratML)** – a data interoperability standard for sharing information about organizational strategy and planning efforts.

<http://www.xml.gov/stratml>

**Systematized Nomenclature of Medicine (SNOMED-CT ®)** - a comprehensive clinical terminology and infrastructure that enables a consistent way of capturing, sharing, and aggregating health data across specialties and sites of care. SNOMED was developed by the College of American Pathologists.

<http://www.snomed.org>

**Systematized Nomenclature of Dentistry (SNODENT)** - a systematized nomenclature of dentistry containing dental diagnoses, signs, symptoms, and complaints.

<http://www.ada.org>

**TransXML** - an interoperability standard for the exchange of transportation data, and a framework for development, validation, dissemination, and extension of current and future schemas.

<http://www.transxml.org>

**Unified Medical Language System** - links more than 100 terminologies available for a variety of use cases in health care. It is a multipurpose resource that includes concepts and terms from many different source vocabularies. It is sponsored by the National Library of Medicine.

<http://www.nlm.nih.gov/pubs/factsheets/umls.html>

**United States Health Information Knowledgebase (USHIK)** - a metadata registry of health information data element definitions, values, and information models that enable browsing, comparison, synchronization, and harmonization within a uniform query and interface environment.

<http://www.ushik.org>

**Universal Medical Device Nomenclature System (UMDNS)** - a standard international nomenclature and coding system used to facilitate identifying, processing, filing, storing, retrieving, transferring, and communicating data about medical devices.

<http://www.ecri.org>

**Workgroup for Electronic Data Interchange (WEDI)** - a subgroup of Accreditation Standards Committee X12 that has been involved in developing electronic data interchange standards for billing transactions.

<http://www.wedi.org>



# APPENDIX C

## IDENTIFIED STANDARDS BY SECTOR AND TYPE

### Aging

Reporting Standards
National Aging Program Information System (NAPIS)
Data Interoperability Standards/Suites of Standards
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

### Behavioral Health

Reporting Standards
National Outcome Measures (NOMs)
National Reporting Program for Mental Health Statistics
Treatment Episode Data Set (TEDS)
Uniform Reporting System (URS)
Data Interoperability Standards/Suites of Standards
Overarching Frameworks
Decision Support 2000+
SDOs/Harmonization Efforts
Certification Organizations

# Appendix C

Understanding Human Services Utilization: October 2009

## Child and Family Services

Reporting Standards
Adoption and Foster Care Analysis and Reporting System (AFCARS)
Head Start Program Information Report
National Child Abuse and Neglect Data System (NCANDS)
National Vital Statistics System: Mortality (NVSS-M)
National Vital Statistics System: Natality (NVSS-N)
National Youth in Transition Database
Pediatric Nutrition Surveillance System (PedNSS)
Pregnancy Nutrition Surveillance System (PNSS)
Runaway and Homeless Youth Management Information System (RHYMIS)
Statewide Automated Child Welfare Information Systems (SACWIS)
Data Interoperability Standards/Suites of Standards
Child Support and Court/Judicial Message Exchange Data Model
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

## Community Resources

Reporting Standards
Data Interoperability Standards/Suites of Standards
Alliance of Information and Referral Systems Standard (AIRS XSD)
National Information Exchange Model (NIEM)
Overarching Frameworks
National Information Exchange Model (NIEM)
SDOs/Harmonization Efforts
Certification Organizations

## Corrections

Reporting Standards
Data Interoperability Standards/Suites of Standards
Corrections Technology Association Corrections Data Exchange Standards Project National Information Exchange Model (NIEM)
Overarching Frameworks
National Information Exchange Model (NIEM)
SDOs/Harmonization Efforts
Certification Organizations

## Criminal Justice/Courts

Reporting Standards
Uniform Crime Reports (UCR)/National Incident-Based Reporting System (NIBRS)
Data Interoperability Standards/Suites of Standards
Child Support and Court/Judicial Message Exchange Data Model Law Enforcement Information Sharing Program (LEISP) Exchange Specifications (LEXS) N-DEx: Law Enforcement National Data Exchange National Information Exchange Model (NIEM)
Overarching Frameworks
Justice Reference Architecture (JRA) National Information Exchange Model (NIEM)
SDOs/Harmonization Efforts
Certification Organizations



# Appendix C

Understanding Human Services Utilization: October 2009

## Emergency/Disaster

Reporting Standards
Disaster Surveillance Forms
Epidemic Information Exchange (Epi-X)
Health Alert Network (HAN)
National Electronic Disease Surveillance System (NEDSS)
Data Interoperability Standards/Suites of Standards
Common Alerting Protocol (CAP)
Coordinated Assistance Network Standard (CAN XML)
Emergency Data Exchange Language (EDXL)
National Information Exchange Model (NIEM)
Overarching Frameworks
National Information Exchange Model (NIEM)
SDOs/Harmonization Efforts
ANSI-Homeland Security Standards Panel (ANSI-HSSP)
Certification Organizations

## Employment/Workforce Training

Reporting Standards
Workforce Investment Act Data Reporting and Validation System (DRVS)
Data Interoperability Standards/Suites of Standards
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

## Food and Nutrition Programs

Reporting Standards
Pediatric Nutrition Surveillance System (PedNSS)
Pregnancy Nutrition Surveillance System (PNSS)
Supplemental Nutrition Assistance Program (SNAP)
Women, Infants, and Children Program (WIC)
Data Interoperability Standards/Suites of Standards
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

## Health care

Reporting Standards
Clinical Reporting System (CRS)
Medicaid Analytic Extract (MAX)
Medicare Data Files
Ryan White Program
SCHIP Statement of Expenditures (CMS-21)
Data Interoperability Standards/Suites of Standards
ASC X 12N Transaction
Continuity of Care Document (CCD)
Continuity of Care Record (CCR)
Health Level Seven (HL7)
National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT)
Overarching Frameworks
Clinical Document Architecture (CDA)
Medicaid IT Architecture (MITA)
Nationwide Health Information Network (NHIN)
SDOs/Harmonization Efforts
Consolidated Health Informatics (CHI)
Electronic Healthcare Network Accreditation Commission (EHNAC)
Federal Health Architecture (FHA)
Health Information Technology Standards Panel (HITSP)
Integrating the Healthcare Enterprise (IHE)
National Committee on Vital and Health Statistics (NCVHS)
National eHealth Collaborative
Certification Organizations
Certification Commission for Healthcare Information Technology (CCHIT)

# Appendix C

Understanding Human Services Utilization: October 2009

## Housing/Shelter

Reporting Standards
Client Activity Reporting System (CARS) Form HUD-50058 Low Income Home Energy Assistance (LIHEAP) Program Performance Weatherization Assistance Program (WAP)
Data Interoperability Standards/Suites of Standards
Homeless Management Information System XML (HUD HMIS XML)
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

## Income Support

Reporting Standards
Temporary Assistance for Needy Families (TANF) and Tribal TANF
Data Interoperability Standards/Suites of Standards
Overarching Frameworks
SDOs/Harmonization Efforts
Certification Organizations

## Public Health

Reporting Standards
Disaster Surveillance Forms
Epidemic Information Exchange (Epi-X)
Health Alert Network (HAN)
National Electronic Disease Surveillance System (NEDSS)
National Vital Statistics System: Mortality (NVSS-M)
National Vital Statistics System: Natality (NVSS-N)
Pediatric Nutrition Surveillance System (PedNSS)
Pregnancy Nutrition Surveillance System (PNSS)
Data Interoperability Standards/Suites of Standards
Public Health Information Network (PHIN)
Overarching Frameworks
SDOs/Harmonization Efforts
Public Health Data Standards Consortium (PHDSC)
Certification Organizations



# APPENDIX D

## ALPHABETICAL LISTING OF STANDARDS

STANDARD NAME	IF FEDERAL SPONSOR	
	DEPT	AGENCY
Adoption and Foster Care Analysis and Reporting System (AFCARS)	HHS	ACF
Alliance of Information and Referral Systems Standard (AIRS XSD)		
ANSI-Homeland Security Standards Panel (ANSI-HSSP)	HSEC	Science & Technology Dir
ASC X 12N Transaction		
Certification Commission for Healthcare Information Technology (CCHIT)		
Child Support and Court/Judicial Message Exchange Data Model	HHS	ACF
Client Activity Reporting System (CARS)	HUD	FHA
Clinical Document Architecture (CDA)		
Clinical Reporting System (CRS)	HHS	IHS
Common Alerting Protocol (CAP)		
Consolidated Health Informatics (CHI)	OMB	
Continuity of Care Document (CCD)		
Continuity of Care Record (CCR)		
Coordinated Assistance Network Standard (CAN XML)		
Corrections Technology Association Corrections Data Exchange Standards Project		
Decision Support 2000+	HHS	SAMHSA
Disaster Surveillance Forms	HHS	CDC
Electronic Healthcare Network Accreditation Commission		
Emergency Data Exchange Language (EDXL)	HSEC	Science & Technology Dir
Epidemic Information Exchange (Epi-X)	HHS	CDC
Federal Health Architecture (FHA)	HHS	ONC
Form HUD-50058	HUD	Public and Indian Housing
Head Start Program Information Report	HHS	ACF
Health Alert Network (HAN)	HHS	CDC
Health Information Technology Standards Panel (HITSP)		
HL7		
Homeless Management Information System XML (HUD HMIS XML)	HUD	OCPD

# Appendix D

Understanding Human Services Utilization: October 2009

Integrating the Healthcare Enterprise (IHE)		
Justice Reference Architecture (JRA)	JUSTICE	Ofc of Justice
Law Enforcement Information Sharing Program (LEISP) Exchange Specifications (LEXS)	JUSTICE	Ofc of Justice
Low Income Home Energy Assistance (LIHEAP) Program Performance	HHS	ACF
Medicaid Analytic Extract (MAX)	HHS	CMS
Medicaid IT Architecture	HHS	CMS
Medicare Data Files	HHS	CMS
National Aging Program Information System (NAPIS)	HHS	AoA
National Child Abuse and Neglect Data System (NCANDS)	HHS	ACF
National Committee on Vital and Health Statistics (NCVHS)	HHS	NCVHS
National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT)		
National eHealth Collaborative		
National Electronic Disease Surveillance System (NEDSS)	HHS	CDC
National Information Exchange Model (NIEM)	HSEC & JUSTICE	Science & Technology Dir
National Outcome Measures (NOMs)	HHS	SAMHSA
National Reporting Program for Mental Health Statistics	HHS	SAMHSA
National Vital Statistics System: Mortality (NVSS-M)	HHS	CDC
National Vital Statistics System: Natality (NVSS-N)	HHS	CDC
National Youth in Transition Database	HHS	ACF
Nationwide Health Information Network (NHIN)	HHS	ONC
N-DEX: Law Enforcement National Data Exchange	JUSTICE	FBI
Pediatric Nutrition Surveillance System (PedNSS)	HHS	CDC
Pregnancy Nutrition Surveillance System (PNSS)	HHS	CDC
Public Health Data Standards Consortium (PHDSC)		
Public Health Information Network (PHIN)	HHS	CDC
Runaway and Homeless Youth Management Information System (RHYMIS)	HHS	ACF
Ryan White Program	HHS	HRSA
SCHIP Statement of Expenditures (CMS-21)	HHS	CMS
Statewide Automated Child Welfare Information Systems (SACWIS)	HHS	ACF
Supplemental Nutrition Assistance Program (SNAP)	AG	FNS
Temporary Assistance for Needy Families (TANF) and Tribal TANF	HHS	ACF
Treatment Episode Data Set (TEDS)	HHS	SAMHSA



# Appendix D

Understanding Human Services Utilization: October 2009

Uniform Crime Reports (UCR)/National Incident-Based Reporting System (NIBRS)	JUSTICE	FBI
Uniform Reporting System (URS)	HHS	SAMHSA
Weatherization Assistance Program	DOE	OERE
Women, Infants, and Children Program (WIC)	AG	FNS
Workforce Investment Act Data Reporting and Validation System (DRVS)	LABOR	ETA







	SECTOR													
STANDARD NAME	Aging	BH	Child	Community	Corrections	Crime	Emg/ Disaster	Work	Food	Health	Housing	Income	Public Health	TOTAL
Adoption and Foster Care Analysis and Reporting System (AFCARS)			1											1
Alliance of Information and Referral Systems Standard (AIRS XSD)				1										1
ANSI-Homeland Security Standards Panel (ANSI-HSSP)							1							1
ASC X 12N Transaction										1				1
Certification Commission for Healthcare Information Technology (CCHIT)										1				1
Child Support and Court/Judicial Message Exchange Data Model			1			1								2
Client Activity Reporting System (CARS)											1			1
Clinical Document Architecture (CDA)										1				1
Clinical Reporting System (CRS)										1				1
Common Alerting Protocol (CAP)							1							1
Consolidated Health Informatics (CHI)										1				1
Continuity of Care Document (CCD)										1				1
Continuity of Care Record (CCR)										1				1
Coordinated Assistance Network Standard (CAN XML)							1							1
Corrections Technology Association Corrections Data Exchange Standards Project					1									1
Decision Support 2000+		1												1
Disaster Surveillance Forms							1						1	2
Electronic Healthcare Network Accreditation Commission										1				1
Emergency Data Exchange Language (EDXL)							1							1

STANDARD NAME	SECTOR													TOTAL
	Aging	BH	Child	Community	Corrections	Crime	Emg/ Disaster	Work	Food	Health	Housing	Income	Public Health	
Epidemic Information Exchange (Epi-X)							1						1	2
Federal Health Architecture (FHA)										1				1
Form HUD-50058											1			1
Head Start Program Information Report			1											1
Health Alert Network (HAN)							1						1	2
Health Information Technology Standards Panel (HITSP)										1				1
HL7										1				1
Homeless Management Information System XML (HUD HWS XML)											1			1
Integrating the Healthcare Enterprise (IHE)										1				1
Justice Reference Architecture (JRA)						1								1
Low Enforcement Information Sharing Program (LEIS) Exchange Specifications (LEIS)						1								1
Low Income Home Energy Assistance (LIHEAP) Program Performance											1			1
Medicaid Analytic Extract (MAX)										1				1
Medicaid IT Architecture										1				1
Medicare Data Files										1				1
National Aging Program Information System (NAPIS)	1													1
National Child Abuse and Neglect Data System (NCANDS)			1											1
National Committee on Vital and Health Statistics (NCVHS)										1				1

# Appendix D

	SECTOR													
STANDARD NAME	Aging	BH	Child	Community	Corrections	Crime	Emg/ Disaster	Work	Food	Health	Housing	Income	Public Health	TOTAL
National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT)										1				1
National eHealth Collaborative										1				1
National Electronic Disease Surveillance System (NEDSS)							1						1	2
National Information Exchange Model (NIEM)				1	1	1	1							4
National Outcome Measures (NOMs)		1												1
National Reporting Program for Mental Health Statistics		1												1
National Vital Statistics System: Mortality (NVSS-M)			1										1	2
National Vital Statistics System: Natality (NVSS-N)			1										1	2
National Youth in Transition Database			1											1
Nationwide Health Information Network (NHIN)										1				1
N-DEX: Law Enforcement National Data Exchange						1								1
Pediatric Nutrition Surveillance System (PedNSS)			1						1				1	3
Pregnancy Nutrition Surveillance System (PNSS)			1						1				1	3
Public Health Data Standards Consortium (PHDSC)													1	1
Public Health Information Network (PHIN)													1	1
Runaway and Homeless Youth Management Information System (RHYMIS)			1											1
Ryan White Program										1				1
SCHIP Statement of Expenditures (CMS-21)										1				1

SECTOR														
STANDARD NAME	Aging	BH	Child	Community	Corrections	Crime	Eng/ Disaster	Work	Food	Health	Housing	Income	Public Health	TOTAL
Statewide Automated Child Welfare Information Systems (SACWIS)			1											1
Supplemental Nutrition Assistance Program (SNAP)									1					1
Temporary Assistance for Needy Families (TANF) and Tribal TANF												1		1
Treatment Episode Data Set (TEDS)		1												1
Uniform Crime Reports (UCR)/ National Incident-Based Reporting System (NIBRS)						1								1
Uniform Reporting System (URS)		1												1
Weatherization Assistance Program											1			1
Women, Infants, and Children Program (WIC)									1					1
Workforce Investment Act Data Reporting and Validation System (DRVS)								1						1
TOTAL	1	5	11	2	2	6	9	1	4	21	5	1	10	78

# Appendix D

# Appendix D

Understanding Human Services Utilization: October 2009

STANDARD NAME	TYPE					
	Reporting	Data Interop	Overarch	SDOs/ Harm	Cert Org	TOTAL
Adoption and Foster Care Analysis and Reporting System (AFCARS)	1					1
Alliance of Information and Referral Systems Standard (AIRS XSD)		1				1
ANSI-Homeland Security Standards Panel (ANSI-HSSP)				1		1
ASC X 12N Transaction		1				1
Certification Commission for Healthcare Information Technology (CCHIT)					1	1
Child Support and Court/Judicial Message Exchange Data Model		1				1
Client Activity Reporting System (CARS)	1					1
Clinical Document Architecture (CDA)			1			1
Clinical Reporting System (CRS)	1					1
Common Alerting Protocol (CAP)		1				1
Consolidated Health Informatics (CHI)				1		1
Continuity of Care Document (CCD)		1				1
Continuity of Care Record (CCR)		1				1
Coordinated Assistance Network Standard (CAN XML)		1				1
Corrections Technology Association Corrections Data Exchange Standards Project		1				1
Decision Support 2000+			1			1
Disaster Surveillance Forms	1					1
Electronic Healthcare Network Accreditation Commission				1		1
Emergency Data Exchange Language (EDXL)		1				1
Epidemic Information Exchange (Epi-X)	1					1
Federal Health Architecture (FHA)				1		1
Form HUD-50058	1					1
Head Start Program Information Report	1					1
Health Alert Network (HAN)	1					1
Health Information Technology Standards Panel (HITSP)				1		1
HL7		1				1
Homeless Management Information System XML (HUD HMIS XML)		1				1
Integrating the Healthcare Enterprise (IHE)				1		1
Justice Reference Architecture (JRA)			1			1
Law Enforcement Information Sharing Program (LEISP) Exchange Specifications (LEXS)		1	1			2
Low Income Home Energy Assistance (LIHEAP) Program Performance	1					1
Medicaid Analytic Extract (MAX)	1					1
Medicaid IT Architecture			1			1

# Appendix D

Understanding Human Services Utilization: October 2009

STANDARD NAME	TYPE					TOTAL
	Reporting	Data Interop	Overarch	SDOs/Harm	Cert Org	
Medicare Data Files	1					1
National Aging Program Information System (NAPIS)	1					1
National Child Abuse and Neglect Data System (NCANDS)	1					1
National Committee on Vital and Health Statistics (NCVHS)				1		1
National Council for Prescription Drug Program SCRIPT (NCPDP SCRIPT)		1				1
National eHealth Collaborative				1		1
National Electronic Disease Surveillance System (NEDSS)	1					1
National Information Exchange Model (NIEM)		1	1			2
National Outcome Measures (NOMs)	1					1
National Reporting Program for Mental Health Statistics	1					1
National Vital Statistics System: Mortality (NVSS-M)	1					1
National Vital Statistics System: Natality (NVSS-N)	1					1
National Youth in Transition Database	1					1
Nationwide Health Information Network (NHIN)			1			1
N-DEx: Law Enforcement National Data Exchange		1				1
Pediatric Nutrition Surveillance System (PedNSS)	1					1
Pregnancy Nutrition Surveillance System (PNSS)	1					1
Public Health Data Standards Consortium (PHDSC)				1		1
Public Health Information Network (PHIN)		1				1
Runaway and Homeless Youth Management Information System (RHYMIS)	1					1
Ryan White Program	1					1
SCHIP Statement of Expenditures (CMS-21)	1					1
Statewide Automated Child Welfare Information Systems (SACWIS)	1					1
Supplemental Nutrition Assistance Program (SNAP)	1					1
Temporary Assistance for Needy Families (TANF) and Tribal TANF	1					1
Treatment Episode Data Set (TEDS)	1					1
Uniform Crime Reports (UCR)/National Incident-Based Reporting System (NIBRS)	1					1
Uniform Reporting System (URS)	1					1
Weatherization Assistance Program	1					1
Women, Infants, and Children Program (WIC)	1					1
Workforce Investment Act Data Reporting and Validation System (DRVS)	1					1
<b>TOTAL</b>	<b>33</b>	<b>16</b>	<b>7</b>	<b>9</b>	<b>1</b>	<b>66</b>



